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Meeting the needs of families living with children  
diagnosed with Autism Spectrum Disorder

Mickey Keenan, Karola Dillenburger, Alvin Doherty, Tony Byrne, & Stephen Gallagher  
2007

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Mickey Keenan,  
Karola Dillenburger,  
Alvin Doherty,  
Tony Byrne,  
&  
Stephen Gallagher

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2007

This research is dedicated to all children, young people, and adults diagnosed with Autism Spectrum Disorder, their families, and the professionals committed to helping these families.

“Science is a way of thinking much more than it is a body of knowledge.” Carl Sagan

Copies of this report can be obtained from  
Dr. M. Keenan  
School of Psychology  
University of Ulster  
Coleraine  
N. Ireland BT52 1SA  
E’mail [m.keenan@ulster.ac.uk](mailto:m.keenan@ulster.ac.uk)

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## Foreword

As a parent of two children diagnosed with Autism Spectrum Disorder I have had my eyes opened over the last ten years with respect to the poor provision for children with disabilities in general. In particular, I have been dismayed by the lack of joined-up thinking between the powers that be in Health and Education and the sometimes non-existence of evidence-based-practice. One would think that in the year 2007, in a so-called developed country, we would have a priority to help our disadvantaged children. It may be that Northern Ireland has suffered from years of political unrest and the social and educational needs of our children and families have been set to one side. However, today we still seem to be in the same mindset with continuing reviews, working groups and task groups presenting endless recommendations to the bookshelves. Most of these have been based on the opinions of professionals working in the field and one gets the impression that the consultations and reviews set out to show that what we already have is effective. However, ask any parent of a child with autism and they will tell you that the provision for their child and family falls far short of what they need. The politicians seem to be far removed from reality and more concerned with scoring political points than addressing real social need in our community. For far too long now the voice of the parents and carers, who live with the devastating effects of autism, has been ignored. For far too long the voice of the professionals, who work day to day with the families, has been ignored. High-level reports by public servants intrinsically present a conflict of interests. Are they going to conclude that what they have decided is *ineffective*? Terms like ‘best practice’ and ‘evidence-based’ are linked to reports that are nothing more than reviews of professional opinion and carefully selected publications that take no real account of outcomes.

The PEAT (Parents’ Education as Autism Therapists) Charity was established ten years ago with a mission to help children with autism achieve their full potential by providing training in ABA (Applied Behaviour Analysis) to parents and carers. Although PEAT has helped many families over the years, the statutory provision for families living with autism remains poor. The research presented in this report was required to identify and quantify the provision that families are actually receiving and what they think is required in the future. This research was needed to find out how the professionals working on the front line actually view the situation. In fact, PEAT was established with hope that, if we endorsed science-based intervention for our children and evidenced the effectiveness, statutory providers would embrace this evidence-base and implement its practice and eventually there would be no more need for PEAT to exist. However, in many cases, this has actually led to disagreement between parents and professionals. Inaccuracies and acceptance of non-evidence based practice is in part responsible for this conflict and recourse to litigation only results in greater mistrust between the families and the statutory providers.

While this report may make uncomfortable reading for some, it is necessary to show those in positions of power that current services are neither adequate nor effective. The research has allowed PEAT to identify our priorities to help families and to develop a strategy for the next five years. Effective training for parents and carers can help to make a real difference for their kids but they need the full support of Health and Education professionals in their struggle with autism. Let’s work together to give the children their right to effective services and to give families their right to a good quality of life.

Tony Byrne  
Chairperson PEAT

**Meeting the needs of families living with children  
diagnosed with Autism Spectrum Disorder**

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Tony Byrne, & Stephen Gallagher

**Executive summary**

The research conducted for this report is underpinned by a scientific analysis that is holistic in its foundations, and which provides the basis for data-based decision making in relation to issues affecting the child and the family context.

Autism Spectrum Disorder (ASD) is the clinical term for specific pervasive developmental disorders that have a substantial and functionally restrictive effect on the individual and their family, in particular with regard to social interaction and communication. In Northern Ireland (N.I.) and the Republic of Ireland (R.O.I.), an estimated 1 in 100 children are on the autism spectrum.

In line with recommendations of the *Mental Health and Learning Disability Review* (Bamford & McClelland, 2006), a comprehensive needs assessment of parents of children on the autism spectrum, the children, and professionals working with these families was carried out in order to assess services currently provided, identify the needs of families, and to arrive at recommendations to ensure that a holistic perspective on future support and intervention is tailored to the needs of individual child, parent, and family systems. The project aimed to inform future strategic decision making of professionals, policy makers, and researchers. Comparative data were collected in Northern Ireland and the Republic of Ireland. In total, 95 parents representing 100 children with ASD and 67 multi-disciplinary professionals took part. A mixed-methods approach was used; detailed questionnaires supplied quantitative data and focus group discussions contributed qualitative data.

Results indicate a severe lack of statutory service provision, in particular in Northern Ireland; deficiencies in the actualisation of parent-professional partnerships; prolonged waiting times for diagnosis and ‘statementing’ processes; and absence of a coherent view on science-based policy and practice. While parents and professions largely agreed about future needs, there were some discrepancies with regard to the basis of interventions. The research uncovered considerable lack of knowledge and application of the science of behaviour analysis amongst professionals that can be directly linked to the non-inclusion of suitably qualified behaviour analysts in local governmental reviews and reports. This is in stark contrast with international practice (e.g., in USA, Canada, and New Zealand) where applications of behaviour analysis are recognized as the treatment of choice and behaviour analysts are involved in reports and reviews to ensure accuracy. Recommendations identify the application of a scientific approach that offers a common starting point for professionals and families with children on the autism spectrum.

### Key findings<sup>1</sup>:

- Diagnostic and Special Educational Needs Statement (SENS) process took on average 26 months;
- Parents experienced distress and did not receive sufficient support or advice and information during and after diagnosis and SENS;
- Home tuition programmes were run largely by parents on their own, with little input from statutory professionals; data on changes in child behaviour were not included in care and education plan reviews;
- None of the children in this study were in receipt of full-time home tuition fees;
- In N.I., parents were not satisfied with school provision; there were no ABA-based schools;
- In R.O.I., most children attended ABA-based schools; parents were generally satisfied with provision;
- In N.I., statutory bodies did not make provision for ABA services; there were no statutory professionals qualified to supervise ABA programmes;
- Further training is required in ASD and ABA for professionals, parents, and siblings;
- Parents had moved house, or were prepared to move house, to gain appropriate services for their children;
- Families were in receipt of an average of 3 Multi-Disciplinary Team (MDT) services; professionals identified 9 MDT services as defining an appropriate package of support;
- Parents were experiencing significant distress when trying to access home, family, or respite supports, and sought non-statutory support or relied on their family for support instead;
- Most children had education and care plans and these were reviewed on average every 8-9 months; these plans were not always appropriate; parents were not always invited to attend; intervention data were not routinely included;
- Parents and professionals agreed about most problematic child behaviours;
- Having a child with ASD restricted families in pursuing personal, educational, occupational, and employment interests;
- Parents of children with ASD experienced considerably more psychological distress than the general population;
- Parents and professionals identified the need for more ASD and ABA training; shorter diagnostic and 'statementing' process; better inclusion, partnership, and advocacy; and the setting up of ABA-based schools;
- Parents requested more research and information regarding the science of behaviour analysis.

### Recommendations:

#### Diagnosis

1. That the diagnostic process is shortened to a maximum of 90 days, in accord with international guidelines;
2. That internationally recognised measures and assessment tools are used (e.g., ADOS and ADI-R);

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<sup>1</sup> Based on the responses of 95 parents (representing 100 children) and 67 multi-disciplinary professionals.

3. That all staff involved in diagnosis are trained to international standards in the use of validated and reliable diagnostic measures;
4. That one key worker/advocate be appointed to hold key responsibility for each family/child during and after the diagnostic process;
5. That modern technology be used (e.g., two-way mirrors, video recordings) to reduce the number of professionals to which a child is directly exposed;
6. That localised diagnosis and assessment is made available, in order to prevent unnecessary disruption and allow for a more rapid responsive mode of delivery;
7. That a comprehensive database of children with ASD and their families is established;
8. That the concept of ASD as a necessarily life-long disability be revised, in view of changes in behaviour resulting from intervention.

**Early intervention and education:**

9. That SENS are issued speedily in line with the law (i.e., max 18 weeks);
10. That each child's education and care plan is revised regularly, incorporating parental feedback and data derived from interventions;
11. That intervention begins early (i.e., immediately after diagnosis/before the child's 3<sup>rd</sup> birthday) as recommended by international research and the All-Party Parliamentary Group on Autism (APPGA, 2003).
12. That localised intervention is made available to allow for a data-based, prompt, responsive mode of delivery;
13. That a long-term view is taken on the economic impact of intensive early intervention, i.e., that resource allocation decisions are based on national and international cost-benefit analysis;
14. That all children diagnosed with ASD are offered early intensive behavioural intervention for as long as necessary (in accord with international best practice);
15. That statutory bodies take up their responsibility to supply science-based early intervention, i.e., supply and support ABA-based home tuition programmes and day services;
16. That ABA-based schools and classrooms are developed and maintained by statutory education boards;
17. That all ABA-based intervention is supervised by a BCBA/PhD level trained behaviour analysts;
18. That all staff involved are trained to international standards in ASD and ABA.

**Staff training:**

19. That accredited Masters level ABA training is fully supported by statutory education and further education bodies;
20. That a range of ASD and ABA training modules and Continuous Professional Development (CPD) courses are developed and supported;
21. That all CPD and short courses in ABA are taught by BCBA/PhD level trained behaviour analysts;
22. That teachers, teaching assistants, and MDT staff are appropriately trained in ASD and ABA;
23. That staff take into account the fact that modern day parents may be better informed than some of the staff on issues regarding ASD and ABA;
24. That ABA is considered for application in other areas of work (e.g., social work, community work, mental health, behavioural medicine) and that staff are educated about ABA in these areas;

25. That further research is carried out to keep abreast with international advances in science regarding ASD and ABA.

**Parent-professional partnership**

26. That parents' input into the writing and review of care and education plans is comprehensively incorporated, and that data from professionally monitored home tuition programmes are included;
27. That parents are kept fully informed regarding financial, social, home, and respite care provisions, and early intervention;
28. That appropriate home, family, respite, and early intervention supports are available to parents and families;
29. That appropriate financial supports are made available to parents and families;
30. That individual and family needs of siblings and parents are considered in assessment and resource allocation;
31. That the extended family is fully involved in assessment and intervention, where appropriate;
32. That parent training courses are made available for ASD and ABA, taught by BCBA/PhD level trained behaviour analysts;
33. That parents are fully involved in decision making regarding assessment, review, and intervention;
34. That ABA is accurately presented in reports and review, i.e., that appropriately ABA-trained professionals are included on review boards or are fully consulted;
35. That professional competences and boundaries are respected and professional ethics are adhered to.

## **Meeting the needs of families living with children diagnosed with Autism Spectrum Disorder**

### **1. Introduction**

Autism Spectrum Disorder (ASD) is the clinical term for specific pervasive developmental disorders, described in both the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV, 1994) and the International Classification of Diseases-Tenth Revision (ICD-10, 1993), as having a substantial and functionally restrictive effect on the individual and their family (Lockshin et al., 2004), in particular with regard to social interaction and communication (Howlin et al., 2004; Järbrink & Knapp, 2001). The number of children diagnosed with Autism Spectrum Disorder (ASD) is increasing and is estimated to be approximately 1 in 100 (Knapp et al., 2007; Report of Task Group on Autism, 2002). Living with a child diagnosed with ASD poses many challenges for a family. Statutory service provision normally focuses on the needs of the child and in some cases provides respite care in an attempt to help the family unit. Generally parents are told to leave interventions with their child to the professionals. However, insufficient resources and training as well as lack of science-based practice approaches have left many parents dissatisfied with the services provided. The children are not achieving their full potential and families are exposed to tremendous stress. Solity (1991) summarised how system failures can lead to labelling of children:

“[T]here is a tendency to believe that ... children that fail to learn, do so because they have a learning difficulty. It is not often that their failure is attributed to the quality and appropriateness of the learning experiences, themselves.” (p.154)

The charity Parents' Education as Autism Therapists (PEAT) was founded by parents with the aim to bring effective science-based interventions to families living with children diagnosed with ASD, and to allow parents to become pro-active as therapists for their own children and enable them to reach their full potential. The study reported here was undertaken by the University of Ulster and Queen's University of Belfast, in collaboration with and on behalf of PEAT, and funded by the Royal Irish Academy. The research set out to:

- support the development of joined-up thinking between parents and careers; voluntary sector, statutory service providers, and academia;
- collect data that can influence decisions concerning health and education provision;
- collect data that can influence policy maker decisions;
- provide recommendations that should be the basis of improvements in services available to families living with children diagnosed with ASD;
- inform PEAT's strategic planning for the next 5 years.

The study objectives were to

- involve parents and professionals directly, in particular to give parents a voice;
- compare data from Northern Ireland and the Republic of Ireland;
- assess services currently provided to families;
- identify the needs of families living with children diagnosed with ASD;



- work in partnership with academic and voluntary organisations;
- make recommendations to ensure that families living with children diagnosed with ASD receive support tailored to individual needs and circumstances;
- identify indicators for best practice and policy guidance.

The report first outlines the history of the study of autism, prevalence and incidence rates worldwide and in Ireland, aetiology, symptoms, and risk and protective factors. Details are given regarding assessment and diagnosis before financial impact and statutory service provisions are outlined. The reader then is introduced to the basics of the science of behaviour analysis. Following a description of the research methodology, the key results are reported, covering the diagnostic process and the Special Education Needs Statement (SENS), home tuition programmes and parent training, day service and education provisions, teacher qualifications, financial and multi-disciplinary supports, home and respite support, and care and education plans. Finally, child behaviours that cause difficulties and distress to parents, issues around siblings, parents, and family more generally are outlined before more general topics such as the application of ABA to areas other than ASD, psychological well being of the parents, and future needs are drawn out. The discussion of issues that transpire from the findings, in particular regarding prevalence and diagnosis, treatment and intervention, staff and parent training, and parent-professional partnership, is followed by policy and practice recommendations.

We acknowledge in particular the help of the parents and professionals who took the time to complete what turned out to be a very comprehensive (in other words, lengthy) questionnaire and who took part in focus group discussions. This report should be used to inform policy makers and practitioners charged with providing the best possible support for children diagnosed with ASD and that ultimately families and society as a whole will benefit. We would also like to especially acknowledge Evelyn Smith and Leanne Jenkinson for their help with data collection across the length and breadth of Northern Ireland. We also thank Lynsay Mulcahy and Mary Rainey for their help with administration generally and especially with conference organisation. We would like to thank our international colleagues, in particular Prof. Bobby Newman and Prof. Gina Green, for continued support and expert advice. This project is a real example of parent-professional partnership.

## **1.1 History**

The term ‘autism’, derived from the Greek word “autos” meaning “self”, was coined by the Swiss psychiatrist Eugene Bleuler in 1906, to describe behaviours in patients who seemed to consider everything that was going on in the world around them as related to themselves (Ritvo, 1976). The concept of autism in children was introduced in 1943 by the Austrian psychiatrist Leo Kanner (1943). He used the term ‘early infantile autism’ to describe the unusual patterns of behaviour he observed in young children that were characterised by severe impairment in social interaction and communication and an intense resistance to change.

Kanner identified infantile autism as a distinct diagnostic entity when he gave a detailed description of each of the eleven children he had seen at Johns Hopkins University. These children were remarkably alike in several behavioural categories, but were different from the general child clinical population. Specifically, all of the children were unable to develop normal relationships with people (‘extreme autistic aloofness’); showed a delay in

speech acquisition or if speech did develop, it was non-communicative in nature (e.g., echolalic); engaged in repetitive and stereotyped play activities, showed a compulsive need for the maintenance of sameness in the environment, demonstrated a lack of imagination and fantasy, had good rote memory, and were of normal physical appearance. Importantly, these abnormalities appeared in very early infancy.

Around the same time, the Austrian-based practitioner Hans Asperger (1944) described a similar but less impaired group of four children as having a disorder he called ‘autistic psychopathology’. Similar to Kanner (1943), Asperger described the children’s difficulties in social interaction, affective expression, and communication. However, there were some differences. Asperger’s cases had developed good language abilities by the time they entered school, even though they sometimes showed pedantic, adult-like speech, had very poor conversational skills, and/or used unusual volume, tone, and flow of speech. In addition, Asperger noted that these children often displayed original thought and tended to be excessively preoccupied with unusual interests. Because Asperger had written his 1944 paper in German, Asperger syndrome did not receive much international attention until the 1980s, when Wing (1981) provided a clinical description of it in English. Although neither Kanner nor Asperger were aware of each other’s research, the fact they both used the term ‘autistic’ to describe these children was telling.

## **1.2 Defining Autism Spectrum Disorder**

The years immediately following the publication of Kanner’s (1943) article reflected an uncertainty in the evolution of appropriate terminology. New labels were being introduced according to people’s view on the aetiology (cause) and nature of autism (Schopler & Rutter, 1978), such as ‘childhood psychosis’ or ‘borderline psychosis’ (Ekstein & Wallerstein, 1954) and ‘childhood schizophrenia’ (Bender, 1956). Yet, no consensus was achieved on how to differentiate children with these labels.

One contributing factor to this confusion was the notion that autism was an emotional disorder caused by inadequate parenting, especially by mothers, described by Kanner (1943) as ‘rejecting’, ‘obsessive’, ‘intellectual’, and ‘emotionally cold’. The notion of ‘refrigerator parents’, whose ‘aloofness’ and ‘lack of warmth’ was the cause of autism, persisted for the next 30 years mainly through the writings of Bettelheim (1950). The child was thought to interpret parental behaviours as rejection, responding with almost total withdrawal from human contact and becoming an ‘empty fortress’ (Bettelheim, 1970).

A second contributing factor that impeded the development of more formal definitions of autism was the thought that autism may be an early manifestation of schizophrenia. Eventually, however, researchers such as Kolvin et al (1971) suggested that autism was indeed a distinctive condition in terms of its clinical features, course, and family history (Volkmar, 1998) and that there should be consistency in terminology in relation to children who had some or all of the clinical features of Kanner’s earlier cases, i.e., onset before thirty months of age, impaired social development, delayed and/or deviant language development, and insistence on sameness. However, unlike Kanner (1943), who made a clear distinction between learning disability and autism, Rutter (1978) found that, according to conventional IQ tests, most children who met the criteria for autism were also intellectually impaired. Accordingly, these were not mutually exclusive diagnoses and in order to avoid ambiguity he suggested that ‘childhood autism’ criteria should be adopted (Bishop, 1989).

The idea of autism as a spectrum disorder, covering a range of ability levels but characterised by a qualitative 'triad of impairments' in social, communicative, and imaginative development was introduced by Wing and Gould (1979). When they examined children who had special needs, they found autism among nearly 5 per 10,000. However, when they looked at children who showed some aspects of Kanner's original 'infantile autism', they identified around 15 per 10,000 children who showed impairments in the three domains of autism. Although these children did not fit into the full picture of early childhood autism as described by Kanner, they were identified as being within a broader spectrum of disorders or on the 'autism spectrum'. Wing and Gould proposed that Autism Spectrum Disorder (ASD) could be viewed as a life-long developmental disorder, that includes the symptoms described by Kanner and Asperger, but they suggested that it was a much wider category than those used by either of these authors.

The essential point of the concept of a spectrum rather than a distinct disorder was that each aspect of the 'triad of impairments' (Wing, 1979/1996) could occur in widely varying degrees of severity and in many different manifestations. For example, social impairment could be passivity in social interactions, or active, but inappropriate and repetitive approaches to others, not just aloofness as in Kanner's original definition (Wing & Potter, 2002). Often a heightened sensitivity to sound, smells, touch, taste, and visual stimulation is also present (Jordan, 1999). The following description of the triad of impairments typical for ASD is now commonly accepted:

- *Social interaction* - impaired, deviant and delayed, or atypical social development, especially interpersonal development, varying from 'autistic aloofness' to 'active but odd'.
- *Language and communication* - impaired and/or deviant, verbal and non-verbal, deviant semantic and pragmatic aspects of language.
- *Thought and behaviour* - rigidity of thought and behaviour and impoverished social imagination, ritualistic behaviour, reliance on routines, extreme delay or absence of pretend play.

One of the main criteria for diagnosis is that the above behaviours must be out of keeping with what is typically expected of an individual of the same age and that they are displayed in the long-term (not just once off) (Frith, 1989). Manifestations of the triad of impairments vary between individuals and change across time.

### **1.3 Evolution of diagnostic systems**

Wing (1979/1996) suggested that ASD, rather than being linked with schizophrenia as originally proposed by Kanner (1943), more often concurred with learning disability, and that the triad of impairments was found in other conditions such as more general 'pervasive developmental disorders'. The term pervasive developmental disorder (PDD) was included in the official classification system of the American Psychiatric Association (DSM-III, 1980). PDD was considered to be a generic label comprising several different conditions including autism, childhood onset pervasive developmental disorder, residual autism and atypical autism (American Psychiatric Association, 1980). The term referred to the idea that the impairments in socialization, communication and play, 'pervades' all aspects of a child's life and that they arise from developmental disability and not a psychiatric disorder. Adoption of PDD was viewed as a significant move forward because

“it places emphasis on the developmental aspect or characteristics of the abnormalities, and in its highlighting of the differentiation from mental illness as they occur in adult life.” (Rutter & Schopler, 1987, p. 160)

The adjective ‘pervasive’ draws attention to the widespread distortion of the developmental process. However, some clinicians are hesitant in the use of this term, because although some developmental processes are affected by the disorder, others may be unaffected, and therefore PDD should not be considered ‘all-pervasive’.

“Indeed, it is the very fact that general intelligence may be relatively spared ... that underlines the need to separate autism from global mental handicap.” (Rutter & Schopler 1987, p. 161)

The original inclusion of ‘autism’ in the DSM-III (1980) represented the recognition of autism as a diagnostic category, as part of a more general group of disorders that shared some essential features but differed on symptom patterns or aetiology. However, problems with DSM-III were widely recognised (Rutter & Shaffer, 1980), in particular its lack of sensitivity, as a substantial number of children who were thought to ‘have autism’ did not meet the stringent DSM-III criteria (Volkmar et al., 1986).

Revisions in DSM-III-R definition of autism meant that although sensitivity was now very high, specificity still was quite low (Factor et al., 1989; Hertzog et al., 1990; Szatmari, 1992). In other words, a large number of children previously not diagnosed, now met the diagnostic criteria for autism. Importantly, though, there were differences between DSM-III-R and the 10<sup>th</sup> draft revision of the ICD (Volkmar et al., 1992). These problems led to large field trials and the inclusion of Rett’s Disorder, Childhood Disintegrative Disorder, Asperger Syndrome, and Pervasive Developmental Disorder – Not otherwise Specified (PDD-NOS) (Buitelaar et al., 1999). Subsequently, the DSM-IV and the ICD-10 had conceptually identical definitions as well as acceptable levels of sensitivity and specificity for ASD (Volkmar et al., 1994; Volkmar, 1998). Key elements of the revised criteria included the presence of severe and pervasive impairments in social interaction and communication, development of unusual interests and stereotyped patterns of behaviour, and it was stipulated that the onset occurred prior to 3 years of age (Buitelaar et al., 1999).

Differences remain between the two classification systems. The ICD-10 includes ASD under the broader heading of Pervasive Developmental Disorders (PDD) that are characterized by qualitative abnormalities in reciprocal social interactions and patterns of communication, and by restricted, stereotyped, repetitive repertoire of interests and activities. They include:

- *Childhood (classical) autism* (F84.0) is defined by the presence of abnormal or impaired development that is manifest before the age of three years, and the characteristic type of abnormal functioning in all three areas of the triad of impairment. DSM-IV defines this as autistic disorders (AD).
- *Atypical autism* (F84.1) is the term used when a disorder differs from classical autism due to a later age of onset, and includes atypical or sub-threshold symptoms, or both. This category is sometimes referred to as ‘Pervasive Developmental Disorder-Not Otherwise Specified’ (PDD-NOS).

- *Asperger syndrome* (AS) (F84.5) is characterised by the same type of abnormalities in reciprocal social interaction and restricted, stereotyped, repetitive patterns of interest and activities that typify autistic disorder. However, it differs primarily in that there is no clinically significant delay in spoken or receptive language or in cognitive development. There is no requirement to have had developmental difficulties before 3 years of age (CSDE, 2005).

Based upon the DSM-IV, the major diagnostic subgroups within ASD are as follows:

- *Childhood disintegrative disorder* (CDD; 299.10 DSM-IV) is characterised by normal development for at least the first two years, with subsequent significant loss of previously acquired skills.
- *Rett's disorder* (299.80 DSM-IV) is progressive disorder which to date, has been found only in girls. A period of normal development is then followed by loss of previously acquired skills, e.g., purposeful use of hands is replaced with repetitive hand movements beginning at the age of 1-4 years.
- *Autistic disorder* (299.00 DSM-IV) refers to impairments in social interaction, communication, and imagination play prior to age of 3 years and includes stereotyped behaviours, interests and activities.
- *Pervasive developmental disorder- Not otherwise specified* (PDD-NOS; 299.80 DSM-IV) is commonly referred to as atypical autism. A diagnosis of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but demonstrates a severe and pervasive impairment in specific behaviours.
- *Asperger disorder* (299.80 DSM-IV) is characterised by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, usually with average to above average intelligence (CSDE, 2005).

Although these categories are still beleaguered by a number of conceptual and practical problems, such as the use of dimensionally-based assessment instruments (cf. Volkmar, 1998), they do enhance communication among clinicians and researchers, ensure reliability and validity of research findings, help frame research questions, and more generally assist clinicians and investigators to define autism (Cantwell, 1996; Volkmar, 1998).

## 1.4 Summary

The diagnostic category of ASD emerged relatively recently in diagnostic manuals. The now commonly accepted ASD triad of impairments includes problems in social interaction, language and communication problems, and rigidity of thought and behaviour. Repeated revisions of diagnostic criteria have lead to a definition of autism spectrum that includes CDD, Rett's disorder, Autistic disorder, PDD-NOS, and Asperger disorder/syndrome.

## 2. Prevalence and incidence rates

The question of prevalence and incident rates of ASD, and whether or not these are rising, has preoccupied the literature over the past decade. Are statements such as the following true or are they just media hype?

“We are in the midst of an Autism epidemic” (ehealthy, 2002).

“A threefold increase in autism rates” (Irish Times, 2001a, p.7).

“A tenfold increase in the incidence of autism in children” (Irish Times, 2001b, p.13).

“The Autism explosion” (Autism Research Review Institute, 1999).

Before addressing the issue in detail, it is important to clarify terms. The term ‘incidence’ refers to the number of individuals in a specified population in whom the condition under investigation appeared within a specified time period, e.g., one year. The term ‘prevalence’ refers to the number of individuals in a specified population who have the condition under investigation at a specified time, e.g., one particular day, regardless of when it began (Wing & Potter, 2002).

Table I offers a summary across 40 years of estimated prevalence rates for children with autistic disorder, Asperger syndrome, CDD, and PDD-NOS (Fombonne, 2005a). The table also illustrates the diagnostic criteria used and the country within which each study took place.

**Table I: Prevalence rates of ASD between 1966-2007.**

Reference	Year	Country	Diagnostic Criteria	Rate / 10,000
<b>A. Autistic disorder</b>				
Lotter	1966	UK	Rating Scale	4.1
Wing et al.	1976	UK	Lotter’s rating scale	4.8
Wing & Gould	1979	UK	Kanner / Triad	4.6/15.7
McCarthy et al.	1984	Ireland	Kanner	4.3
Burd et al.	1987	USA	DSM-III	3.26
Gillberg et al.	1991	Sweden	DSM-III-R	9.5
Fombonne et al.	1992	France	Clinical – ICD -10	4.9
Honda et al.	1996	Japan	ICD-10	21.08
Arvidsson et al.	1997	Sweden	ICD-10	46.4
Baird et al.	2000	UK	ICD-10	30.8
Bertrand et al.	2001	USA	DSM-IV	40.5
<b>B. Asperger syndrome</b>				
Ehlers & Gillberg	1993	Sweden	<sup>1</sup> Gillberg’s	36.0 + 35.0
Kadesjo et al	1999	Sweden	DSM-III – R / ICD-10,	48.4
Webb et al.	2003	Wales	ICD-10	20.0
Baird et al	2000	UK	ICD-10, DSM-IV	3.1
Chakrabarti et al	2001	UK	ICD-10, DSM-IV	8.4
Chakrabarti et al	2005	UK	ICD-10, DSM-IV	11.0
<b>C. Childhood disintegrative disorder</b>				
Burd et al	1987	USA	DSM-III	1.11
Sponheim et al	1998	Norway	Interviews & CARS, ABC	1.52
Magnusson et al	2001	Iceland	Mostly ICD-10	2.34
Chakrabarti et al	2001	UK	WPPSI, ICD-10, DSM-IV	6.4
Chakrabarti et al	2005	UK	WPPSI, ICD-10, DSM-IV	9.2
<b>D. Combined pervasive developmental disorders</b>				
Bertrand et al.	2001	USA	DSM-IV	67.0
Green et al.	2005	UK	ICD-10	90.0
Chakrabarti et al.	2005	UK	DSM-IV	59.0
Baird et al.	2006	UK	ICD-10	116.1
CDC	2007	USA	DSM-IV	67.0

(Adapted from Fombonne, 2005)

According to Table I, prior to 1990 estimated prevalence rates for autistic disorder ranged from 3.26 to 4.8 per 10,000. During the early 1990’s this figure remained relatively stable until the late 1990’s, when estimates rose to 21 - 46 per 10,000. Research on prevalence of

Asperger syndrome is limited, possibly because until recently it was considered a separate diagnostic category and this inconsistency is reflected in rates ranging between 3.1 to 48.4 per 10,000. In respect of CDD, estimated prevalence rates are relatively low and range from 1.1 to 9.2 per 10,000.

PDD-NOS and Rett's disorder are much less studied (not shown in Table I), however increasing recognition has resulted in greater focus on these and Fombonne (2005a) estimated a prevalence rate of 20.8 per 10,000 for PDD-NOS, while Volkmar et al. (2004) obtained prevalence rates for Rett's Disorder of below 1 in every 10,000 children.

The National Autistic Society's Information Sheet (NAS, 2006) indicates, that

“best estimates of the total prevalence of autistic spectrum disorders are those based on studies that focus on the whole spectrum and not just specific sub groups.” (p. 3)

Using DSM-IV criteria and taking the full spectrum into consideration, prevalence rates in the USA (Bertand et al., 2001) were reported as 6.7 per 1000 (equivalent of 67 per 10,000); of these 4.0 per 1000 (40 in 10,000) showed full diagnostic criteria for autistic disorder, while 2.7 per 1000 (27 in 10,000) showed PDD-NOS and Asperger syndrome; these figures were confirmed by the Centers for Disease Control and Prevention (CDC, 2007).

In Great Britain, those who used DSM-IV criteria found similar prevalence rates although the breakdown was somewhat different (Chakrabarti et al., 2005). All ASD were found in 60.6 of 10,000 children, of these full diagnostic criteria for autistic disorder were found in 18.9 per 10,000, PDD-NOS in 31.4 per 10,000, Asperger syndrome in 9.5 per 10,000, and CDD in 0.8 per 10,000.

Studies that used the ICD-10 reported slightly higher overall prevalence rates. For example, the Office of National Statistics of the Mental Health of Children and Young People (Green et al., 2005) reported rates of 0.9% for ASD, equivalent of 90 per 10,000, while Baird et al. (2006) reported a total of 116.1 per 10,000 for all ASD, of which 38.9 per 10,000 were found for childhood autism and 77.2 per 10,000 for other ASD.

## **2.1 The debate - time trends**

Although the above epidemiological studies indicate a significant increase in prevalence rates being reported internationally during 1966-2007, the issue is still debated among researchers with regard to two broad issues: (1) the question as to whether increases in prevalence rates stem from anything other than intentionally broadened diagnostic criteria, improved research methodology, case findings, and increased awareness from the public and professional sectors (Gernsbacher et al., 2005); and (2) the question as to whether a secular increase in the incidence of ASD can be totally ruled out (Fombonne, 2003).

Chakrabarti and Fombonne (2005) advises against drawing direct comparisons between current prevalence rates and past surveys, on the basis that earlier prevalence rates referred to different case definitions, diagnostic criteria, or research criteria to define the research population and determine which individuals are to be included or excluded from a survey (i.e., eligibility). Fombonne (2005b) agrees that subsequent to Kanner's (1943) original paper, autism was generally considered to be a rare condition with prevalence rates ranging



from 4 to 5 per 10,000 (Lotter, 1966; 1967; Brask, 1972; Rutter, 1978; Wing & Gould 1979; Wing et al., 1976). However, during this period, researchers focused on a much narrower definition than that employed today, where relatively high numbers of children are described as having atypical autism or autistic features that would not have met the research criteria employed earlier. As such the broadening of the concept of ASD and the development of more inclusive diagnostic criteria allowed researchers to cast a wider net and consequently increased numbers were recorded.

Evolving definitions have a significant impact on our understanding of prevalence rates and are best illustrated in the work undertaken by Kielinen et al. (2000) who applied different diagnostic criteria to the same group of children (n=39,216). Whilst administering Kanner's original criteria the rate of autism was 2.3 per 10,000; this increased to 6.1 per 10,000 using the ICD-10; the use of DSM-IV criteria further increased the rate to 7.6 per 10,000. These findings illustrate a 3-fold variation in prevalence rates based solely upon varying diagnostic criteria.

Research methodologies obviously also influence findings. Designs include early screening and follow-up (Baird et al., 2000), intense screening and assessment (Chakrabarti & Fombonne, 2001), household surveys about psychiatric disorders (Fombonne et al., 2001), review of administration records (Taylor et al., 1999), ascertainment from multiple sources (Bertrand et al., 2001), and assessment from educational services (Sturmey & Vernon, 2001; Hillman et al., 2000). Fombonne (2003) highlights this issue in a comparison of 8 studies (4 in the United Kingdom and 4 in the United States). Given the geographical background for each of the groups, no significant difference was expected within prevalence estimates for each respective area. However, estimates revealed a six-fold variation in rates in the UK and a fourteen-fold variation in US rates. For example, in the UK, Taylor et al. (1999) used administrative methods to identify their research population and obtained prevalence rates of 10.1 per 10,000, whereas Chakrabarti and Fombonne (2001) employed intensive screening and assessment and obtained prevalence rates of 62.6 per 10,000 (i.e., ratio 1:6).

The use of referral statistics also influences prevalence rates. Referral statistics rely upon databases used by health and educational authorities to monitor the number of people accessing or availing of services over time (Gurney et al., 2003; Croen et al., 2002; Treffert, 1970; Taylor et al., 1999). Fombonne (2005a) cautions against comparisons of current and past prevalence rates on the basis of these statistics. This is because increased awareness among parents and professionals, statutory services provision, and public awareness, as well as changes to social and legislative policies, diagnostic substitution (Shattuck, 2006), and as previously discussed, a broadening of the ASD concept and more inclusive diagnostic tools, have brought about increased numbers of people accessing services. Furthermore, the scientific evidence that has accumulated supporting the efficiency and cost-effectiveness of early intensive behavioural and educational programmes (i.e., programmes based on applied behaviour analysis (ABA)), has intensified the number people seeking early ABA-based interventions for their children (National Research Council, 2001). While these databases play a fundamental role in budgetary allocations, monitoring of services, and future services planning, they only reflect "counts" or number of people availing of services and do not reflect prevalence rates among geographical areas. These figures exclude children currently awaiting a formal diagnosis, people who are independent of services (e.g., people with higher functioning

autism) and people who, for data protection reasons, do not consent to having their details recorded on electronic datasets.

The second question is whether the actual prevalence of ASD has increased due to environmental factors, such as diet, environmental pollutants, antibiotics, or allergies. However, there has been no scientifically validated evidence to support any of these assumptions (Wing & Potter, 2002). During the 1990s public attention was intensified by the suggestion of a link between autism and the mumps, measles and rubella (MMR) vaccine (Wakefield et al., 1998; Wakefield & Montgomery, 2000) and other childhood vaccines containing traces of neurotoxins, such as mercury (though in the UK MMR vaccine no longer contains traces of mercury). Although the probability of these suggestive links enhanced the public's awareness of ASD, epidemiological evidence in support remains negative (Rutter, 2005).

It seems that the jury is still out regarding the possibility of an “autism epidemic”. In order to come to a definitive conclusion data will need to be made available that are collected using the same diagnostic criteria, the same method of data collection, and the same research population across a prolonged period of time.

## **2.2 Prevalence of ASD in Ireland**

Over the past few years there have been numerous reports on ASD worldwide (Larsson, 2005). In Ireland two key governmental reports were published; (1) The Report of the Task Group on Autism (2002) commissioned by the Department of Education, Northern Ireland (N.I.); and (2) The Report of the Task Force on Autism (2001) commissioned by the Department of Education and Science in the Republic of Ireland (R.O.I.). In both reports the authors acknowledge a number of difficulties in obtaining prevalence rates of ASD. The N.I. Report of the Task Group on Autism (2002) identified

- lack of effective data gathering methods;
- differential practices in relation to assessment and diagnosis;
- lack of agreement and debate in relation to appropriate diagnostic criteria; and
- difficulty in differentiating between Autism and Asperger syndrome.

The R.O.I. Report of the Task Force on Autism (2001) identified

- lack of biological marker or medical tests as a basis for diagnosis;
- the extent to which periodic revisions of diagnostic systems affect the number of children to be included as having autism spectrum disorders;
- confusion arising from imprecise use of terms autism, ASD, PDD, Asperger syndrome; and
- absence of comprehensive screening and diagnostic procedures.

It is important to highlight that these issues were not exclusive or unique to Ireland and many of the issues acknowledged by both reports were reminiscent of the issues which fuel the international debate on prevalence and incidence rates. To date, no conclusive study has taken place in N.I. or R.O.I.. Furthermore, no region has a central database that offers one centrally governed dataset representative of all individuals within ASD residing in Local Trusts and/or who are under the jurisdiction of Education and Library Boards (N.I.),

Local Health Authorities (HSE) and/or under the jurisdiction of the Department of Education and Science (R.O.I.). Furthermore, there is no shared register to monitor or collate information specific to individuals with ASD. In the absence of any monitoring procedures and epidemiological research, any information regarding prevalence rates for people with ASD must be based upon the prevalence rates obtained in other epidemiological surveys and then applied to local population estimates.

### 2.3 Northern Ireland

Based upon prevalence estimates for ASD of 91 per 10,000 (NAS, 1997; PAPA, 2001) and a population estimate of 1,691,000 (census date June 30<sup>th</sup> 1999; Northern Ireland Statistics and Research Agency, 2001), the Report of the Task Group on Autism (2002) suggested an estimated 15,388 persons of all ages experience ASD; this figure includes approx. 2,776 school-aged children. In respect of Asperger syndrome, a recent report by Jones et al. (2007) acknowledged the difficulties in obtaining exact prevalence rates. Table II shows available prevalence rates for pupils with Autism, Asperger syndrome, and other communication and interaction problems currently attending schools in N.I..

**Table II: Estimated number of pupils with ASD in N.I..**

	Nursery	Pre-school	Primary	Post primary	Special
Autism	17	13	790	160	751
Asperger syndrome	5	1	476	483	80
Communication and interaction group	611	246	2094	443	2

(Adapted from Statistics and Research Branch of the Department of Education N.I., 2006/07)

In total, 6,172 children and young persons were accounted for in Table 2. However, these figures reflect 'referral statistics', in other words, pupils who have more than one special education need (SEN) would be counted more than once. At the same time, at Key Stages 1 and 2, the majority of children with Autism and Asperger syndrome are categorised under the generic coding 'communication and interaction' and therefore the exact number of children with autism and Asperger syndrome within this category cannot be extracted.

### 2.5 Republic of Ireland

Based on prevalence rates of 15 per 10,000, an initial estimate of persons with autistic disorder in the R.O.I. was 1,516 (ISA, 2001). However, this figure does not include children awaiting a diagnosis and does not reflect recent findings on prevalence rates. In light of this apparent underestimation the figure was revised using a rate of 20 per 10,000 and, given a population estimate in 0-19 years in R.O.I. at that time (1996) of 1,198,960 (CSO, 2001), an estimated 2,398 persons would be diagnosed with autistic disorder. For Asperger syndrome the figure was further revised to 36 per 10,000 and, given a population estimate in 0-19 years in R.O.I. at that time (1996) of 1,198,960 (CSO, 2001), an estimated 6,714 persons would be diagnosed with autistic disorder and Asperger syndrome (Report of the Task Force on Autism, 2001). However, if a prevalence rate of 91 per 10,000 is applied, as it was for N.I. estimates, the figure is 10,910 for children and young people, and 37,392 for the total population, based on total population estimate of 4,109,086 for R.O.I. (Central Intelligence Agency, 2007).

Similar to N.I., the prevalence of Asperger syndrome in the R.O.I. is currently unknown. The Report of the Task Force on Autism (2001) highlights the urgent need for further investigation into the prevalence rates and needs of this population. If international findings on prevalence rates for Asperger syndrome (Ehlers & Gillberg, 1993) are applied at the rate of 36.0 per 10,000, this would mean that an estimated 4,316 children and young people have Asperger syndrome in R.O.I..

However, a recent report from the National Council for Special Education (Flynn, 2007) estimated much higher prevalence rates and stated that nearly 18% of children (n=190,303) in the R.O.I. have special education needs; this is equivalent to almost 1 in every 5 children. This estimation was based on research into physical and sensory as well as intellectual and learning disabilities. The report suggested that 0.56% or 6,026 children experience 'autistic learning disabilities' in ROI. This figure still seems conservative on the basis that 'autistic learning disabilities' suggests that children with higher functioning autism or Asperger syndrome may have been excluded from the statistics. In addition, it is not known what percentage of children with specific learning disabilities (n=64,562) or intellectual disabilities (n=20,597) also exhibited behaviours typically found in children on the autism spectrum. Nevertheless, the figure indicates a three-fold increase compared to estimated prevalence rate cited in the Report of the Task Force on Autism (2001).

## 2.6 Summary

In the absence of unambiguous evidence it remains uncertain if there has been an increase in the incidence of ASD over the decades or not.

Numerous researchers (Gernsbacher et al., 2005; Fombonne, 2005a; Croen et al., 2002) suggest that increased prevalence can be accounted for by (1) broadening the diagnostic criteria, (2) the reclassification of children from the intellectual disability diagnostic category to the Autism category, and (3) greater public awareness and more thorough case findings. However, these researchers do acknowledge that a true increase in the incidence of Autism cannot be totally ruled out or ignored. In any case, ASD is much more common than previously thought.

For the purpose of this report, estimated prevalence rates were based on Bertand et al. (2001), The Centers for Disease Control and Prevention (CDC, 2007), Green et al. (2005), Chakrabarti and Fombonne (2005), Baird et al. (2006), and National Autistic Society (NAS, 2006). Table III represents the estimated prevalence rate of ASD in N.I. and in the R.O.I., based on national census figures for children at or under the age of 18 years.

**Table III: Estimated national prevalence rates of ASD.**

Reference	Rate	N. I.*	R.O.I.**	Total
Bertand et al. (2001)	6.7 /1000	3,089	7,330	10,419
CDC (2007)	6.7 /1000	3,089	7,330	10,419
Green et al. (2005)	90/10,000	4,150	9,849	13,999
Chakrabarti et al. (2005)	60/10,000	2,766	6,566	9,332
Baird et al. (2006)	116/10,000	5,348	12,694	18,042
NAS (2006)	1:100	4,610	10,943	15,553

\*N.I. figures based on population estimate 30<sup>th</sup> June 2005 for children, n=461,082.

\*\*R.O.I. figures based on national census 2006 for children, n=1,094,360.

Based upon these data, the estimated prevalence rate of ASD among children in N.I. ranges from 2,766 to 5,348 and in the R.O.I. the estimated prevalence rate ranges from 6,566 to 12,694. Consequently, for the whole of Ireland the estimated prevalence rate of ASD among children ranges from 9,332 to 18,042.

### **3. Aetiology of Autism Spectrum Disorder**

ASD is diagnosed on the basis of behavioural and developmental features (CSDE, 2005). There is no clear evidence that ASD is due to a single cause and current thinking is that multiple factors are likely to interact in a variety of ways to affect the development of the central nervous system and lead to a final common pathway with the clinical presentations of ASD (Short et al., 1995; PHIS, 2001).

#### **3.1 Genetic components**

In approximately 90% of individuals with ASDs, there is evidence to suggest that complex genetic influences contribute to the development of the disorder or pathogenesis (Bailey et al., 1995; Bolton et al., 1994; Steffenburg & Gillberg, 1986). Rutter (2005) suggests that

“taken together with the population base rate for autism, this implies that the heritability or underlying genetic liability is about 90% - the highest figure among all multifactorial child psychiatric disorders.” (p. 232)

This notion is supported by twin studies that have demonstrated that the probability of identical (monozygotic) twins developing ASD is about 60% as compared with a rate of 5% in fraternal (dizygotic) twins (Bailey et al., 1995; Bolton et al., 1994; Steffenburg & Gillberg, 1986). Furthermore, family studies found increased risk of ASD among first-degree relatives (Bolton et al., 1994; Piven et al., 1997; Szatmari et al., 1998; Murphy et al., 2000). In particular, the concurrence rate of ASD among siblings is about 6%, a rate significantly higher than that reported for the general population (concurrence rate of 0.55; Rutter, 2005). For example, Lauritsen et al. (2005) found that the relative risk of autism in siblings of children with autism is approximately 22-fold, and approximately 13-fold in siblings of children with the broader autism diagnoses. According to Rutter (2005), the reason why most siblings do not have ASD, despite the high heritability, is that they have only some of the relevant genes that increase the susceptibility of ASD.

The only single gene condition with an established association with ASD is Tuberous Sclerosis (Smalley, 1998). Tuberous Sclerosis (TS) is a genetic disorder that occurs in 1 in 10,000 people (PHIS, 2001). It is characterised by benign tumours in the brain and many other organs, such as the skin, kidneys, heart, and lungs (Short et al., 1995). Estimates suggest that TS is found in about 1% to 3% of cases of children diagnosed with ASD (Harrison & Bolton, 1997). Others have suggested that TS exists among 1-4% of individuals with autistic disorder and between 8-14% for the subgroup of autistic individuals with a seizure disorder (Fombonne et al., 1997). Although the association of TS with ASD is well established, its role in terms of causal mechanisms is less well understood (Rutter, 2005). Bolton et al. (2002) states that the association with ASD is particularly marked only when TS is associated with severe intellectual disabilities, severe epilepsy, and locations of tumours in the temporal lobe.

The evidence supporting claims of a specific association between chromosome anomalies and ASD is variable. Initially, the strongest claims concerned a relationship between the Fragile X anomaly and autism (Gillberg & Wahlstorm, 1985). These assertions were based upon two issues. Initially, Fragile X was thought to be highly prevalent and exist among 25% of males with ASD (Bolton & Griffiths, 1997). However, investigations in larger samples of individuals with ASD (Bailey et al., 1993; Chakrabarti & Fombonne, 2001) discovered the prevalence of Fragile X to be much lower than previously thought (i.e., 2-3%). Although this remains a significant association, it is evident that Fragile X anomalies account for a very small proportion of cases of ASD. The second claim was based upon unsatisfactory cell culture methods; however, upon the introduction of DNA procedures, it became clear that the cytological identification of fragile sites led to many false negatives (Gurling et al., 1997). The only other chromosome anomaly to be associated with ASD and to receive empirical investigation (Folstein & Rosen-Sheidley, 2001) is the maternal transmitted interstitial duplications of chromosome 15. Research findings suggest an estimated 5% of individuals with ASD show some form of chromosome anomalies, however these anomalies are quite varied and in some instances their clinical significance remains unclear (Rutter, 2005).

Although these data indicate the existence of a genetic component to the aetiology of ASD, the genetic contribution is complex, as the mode of transmission does not follow recognisable patterns (Szatmari, 2003). Rutter (2005) argues that ASD constitutes a multifactorial disorder, including genetic and non-genetic, environmental factors.

### **3.2 Environmental factors**

A range of pre-natal environmental factors possibly play a role in the development of ASD; these include intrauterine infections and toxins (Nelson, 1991; Rodier & Hyman, 1998; MRC, 2001), hypothyroidism, thalidomide use, valproic acid, cocaine or alcohol use, and congenital cytomegalovirus infection. However, none of these have been prominent in any major study of ASD and Rutter (2005) thought, that “it seems unlikely that they constitute commonly operating risk factors for ASD” (p. 234).

Within the last decade, more attention occurred regarding possible post-natal risk factors for ASD. An early systemic study of a large sample of children with congenital rubella (Chess et al., 1971; Chess, 1977) indicated that these children had developed some form of ASD at a substantially higher rate than children with intellectual disabilities or visual and hearing deficits. However with the administration of worldwide vaccinations, the number of reported cases of congenital rubella has declined as have its links to ASD (MRC, 2001).

Of course the potential for a link between the triple vaccination for mumps, measles and rubella (MMR) or other childhood vaccines containing mercury (Wing & Potter, 2002) and ASD has attracted worldwide attention. The argument concerning the MMR vaccination was based upon the work of one particular group of researchers (Wakefield et al., 1998; Wakefield & Montgomery, 2000) who described what they considered to be a particular form of inflammatory bowel disease. They put forward the hypothesis that this was due to MMR vaccination, which was causing a new variant of ‘regressive’ autism and that the observed rise in rates of autistic disorders was related to this new condition (Wing & Potter, 2002).

Rutter (2005) highlights the expected impact on incidents rates of ASD if indeed MMR vaccinations had a role to play. First, the introduction of the vaccine particularly in countries in which the take-up was rapid and high (i.e., the UK) should be followed by a large step-wise increase in ASD, and this should be followed by a plateau when MMR was stopped (e.g., in Japan); this would then be followed by a drop in rate, in particular of regressive autism. However, the evidence shows that none of these expectations were borne out (Rutter, 2004). Fombonne and Chakrabarti (2001) examined epidemiological data concerning children with autism spectrum disorders, some diagnosed before MMR vaccination and some after. They found no evidence to support a distinct syndrome of MMR-induced autism or ‘autistic enterocolitis’.

The Medical Research Centre Review of Autism Research (MRC, 2001) quoted a number of experts who had analysed published as well as oral presentations of Dr Wakefield, as being unanimous in their conclusions: A casual link between the MMR vaccine and “autistic colitis” and ASD was not proven and current epidemiological evidence did not support this proposed link (MRC, 2000; American Medical Association, 2007; Immunization Safety Review, 2001; American Academy of Paediatrics 2005; Irish Department of Health and Children, 2001). However, they acknowledged that, “this conclusion does not exclude the possibility that MMR vaccine could contribute to ASD in a small number of occurrences” (MRC, 2001, p 28). Wing and Potter (2002) agreed,

“[i]t remains a possibility that MMR vaccination precipitates autism in a small number of children who are vulnerable, perhaps because of genetic loading that would otherwise be insufficient to produce overt autistic disorder” (p.30).

Further research on MMR vaccination obviously is important as parental concerns have led to a drop in the numbers of children being vaccinated, with the consequent danger of epidemics of measles, mumps or rubella, all of which can cause long term disability or death in a small but significant number of children (Wing & Potter, 2002).

The second issue concerns the hypothesis regarding Thimerosal (mercury), a preservative that until recently was used in many vaccines (Rutter, 2005). Exposure to mercury during critical periods of early development can lead to a variety of developmental problems affecting motor skills, such as walking and speech (May, 2000). There have been suggestions that early exposure to Thiomersal may be implicated as a risk factor for ASD (Bernard et al., 2001). Although there are apparent similarities between symptoms characteristic of ASD and mercury poisoning, there is no evidence for elevated levels of mercury in children with ASD (MRC, 2001; Normand & Dallery, 2007). Furthermore, Rutter (2005) suggests that the epidemiological evidence regarding the dangers of Thimerosal is much less than that regarding MMR and again the findings are negative; however, he noted that these data cannot exclude the possibility that either MMR or Thimerosal might pose a risk in a small proportion of unusually susceptible children.

### **3.3 Other risk factors**

Factors, such as developmental delay, dysmorphic features, obstetric complication, unequal sex ratio, and head size (Zwaigenbaum et al., 2002; Miles & Hillman, 2000) are considered to represent non-specific signs that autism is a neuropsychiatric disorder (Szatmari, 2003). In terms of co-morbid medical disorders, evidence now exists that disturbances of the



gastrointestinal system are no more common in children with autism than in the general population of children (Black et al., 2002). Parents of children with autism often report both unusual dietary habits and gastrointestinal symptoms. A systematic dietary examination, however, found adequate intake of calories, carbohydrates and fats, and high intake of protein, with no association between dietary intake and stool density (Levy et al., 2007).

The association between ASD and epilepsy has been recognised since the late 1960s and seizures are a significant cause of morbidity and mortality for individuals with ASD. Estimates of the proportion of individuals affected vary, but by adulthood about one third of individuals with ASD have developed epilepsy (Volkmar & Nelson, 1990). Although the association of ASD and epilepsy is of considerable importance when addressing the needs of individuals with ASD and their families, there is very little evidence to allow the nature of these links to be unravelled (PHIS, 2001).

### 3.4 Summary

ASD is multifactorial condition potentially caused by multiple genes and some, as yet to be identified, non-genetic factors (Rutter, 2005). Epidemiological findings have been helpful in including and excluding various significant factors. Most importantly, however, it is now beyond debate that autism is not caused by poor parenting or an unemotional ‘refrigerator mother’, as previously suggested by Bettelheim (1967).

It is now recognized that “we should not just think about the cause for autism, but about a long causal chain” (Frith, 1991, p.80). Frith suggests a “hazard, havoc, harm model”, where the hazard can include defective or damaged genes, chromosome abnormality, metabolic disorder, viral agents, immune intolerance, and anoxia or other prenatal problems. These hazards can potentially create havoc in neural development and lasting harm may be done to the development of specific brain systems concerned with higher mental processes. The harm may be mild or severe, but always involves the developmental arrest of a clinical system at a critical point in time, when autism is diagnosed (Homles, 1998).

## 4. Symptoms of ASD in early childhood

Commonly, parents of children diagnosed with ASD report becoming aware of atypical development in their children within the first year of life (Baird et al., 2003). In the absence of a biological marker for screening for ASD, parental reports are crucial in the diagnosis process, as parents often deduce that there is a problem in their children’s behaviour prior to anyone else, especially during the early years of development (Hall & Elliman, 2003).

### 4.1 Social relatedness

Individuals with ASD usually experience some kind of social impairment, such as being socially isolated and exhibiting inappropriate social behaviour (Tuchman, 2003). Parents sometimes report their child being “*in his/her own little world*”, with a general lack of interest for others. Most affected children lack social emotional reciprocity with severe impairment in initiation of social activities (Charman & Baird, 2002), although they may participate if others initiate contact (Spence et al., 2004; Nikopoulos & Keenan, 2006).

Parents usually report that their child shows isolation from surroundings, fails to play like other children, has an empty gaze, does not attract attention, has poor imitation of movements, and exhibits apparent deafness (Gillberg et al., 1990). More specifically, within the first year of development, parents report that children with ASD show impairments in social interactions, lack social smile, lack appropriate facial expression, experience hypotonia (abnormally low muscle tone), and show poor attention. In the second year of development, additional impairments became prominent including ignoring people, lack of eye contact, lack of appropriate gestures, and lack of emotional expression (Adrien et al., 1992).

## **4.2 Communication**

Despite the very obvious abnormalities and delays in the development of language in many children, it is communication rather than language difficulties that are characteristic of autism (Jordan & Powell, 1995). One of the key diagnostic features of ASD includes 'qualitative impairments in communication' (DSM-IV, 1994). In Kanner's (1943) original description of 'infantile autism', he noted that all children showed a delay in speech acquisition or if speech did develop it was non-communicative in nature (e.g., echolalia).

The importance of language deficits as a major impairment was acknowledged over thirty years ago. First, Rutter and Lockyer (1967) indicated that apart from intellectual functioning, language acquisition is to be considered the best predictor of psychosocial outcome for children with autism. Rutter (1978) argued that children with autism who had acquired useful language by the age of five years, had an increased prognosis for social adjustment, compared to children with no development or acquisition of language. Second, many of the behavioural difficulties displayed by children with autism such as temper tantrums may be in part due to the child's inability to communicate their wants and desires (La Vigna, 1977).

The verbal and nonverbal communication deficits seen in ASD are varied and complex and range from complete failure to develop expressive and receptive language skills (Manning-Courtney et al., 2003) to fluent speech with specific semantic or pragmatic impairments (Brook & Bowler, 1992; Rapin, 1997). Immediate and delayed echolalia is considered a hallmark feature and usually becomes apparent during pre-school years. Other language deficits can occur either as scripted speech (e.g., repetition of lines/comments used in movies or TV programmes) (Spence et al., 2004) or in individuals with fluent verbal output, as errors in semantics or deficits in social context, such as an inability to initiate or sustain flexible and reciprocal conversation or understand subtleties of language (e.g., jokes, sarcasm) (Tuchman, 2003). In individuals with Asperger syndrome, language generally is superficially intact; however they usually exhibit significant pragmatic deficits with concrete thinking and poor understanding of sarcasm and irony (Spence et al., 2004).

Nonverbal communication deficits include a profound lack of gestures in communication. Oftentimes, children with ASD demonstrate deficits in the appropriate use of eye contact and often fail to engage in attention sharing behaviours, like pointing or showing objects (Tanguay, 2000). In a study involving home-made videos at birthdays (1st birthday) Osterling and Dawson (1994) found that children with autism were less likely to look at others, to show an object or point to objects, and to orient to their name compared to typically developing peers.

### **4.3 Restricted interests and repetitive behaviours**

Individuals with autism oftentimes display sensori-motor gating deficits that, although nonspecific to autism, are associated with the severity of restricted and repetitive behaviours (Perry & Condillac, 2003). Typical repetitive behaviours include opening and closing doors, flipping light switches on and off, and repetitive water play (Spence et al., 2004). Motor stereotypes (i.e., self-stimulating behaviours) usually appear during pre-school years and commonly include finger flicking, hand flapping, body rocking, self spinning, or running in circles. These behaviours have been reported in 37% to 95% of children with ASD (Filipek et al., 2000; Tuchman, 2003). Baranek (1999) demonstrated abnormalities in the orientation to visual stimuli, such as preoccupations with parts or movements of objects (e.g., wheels) as opposed to the whole object (Tuchman, 2003). Changes in the pattern of daily routine, environment, or living schedules have also been reported to elicit behavioural resistance and tantrums in children with ASD (Spence et al., 2004). While Sigman (1998) and Mundy (1995) shift the focus from language to social and orientating behaviours, such as restrictive interests and repetitive behaviours because these are highly characteristic of autism, most studies concur that the best and most likely discriminators are in the area of social and communicative impairments (Charman et al., 1998; Swettenham et al., 1998).

### **4.4 Related problems**

Although sensory abnormalities in children with ASD are not included in the diagnostic criteria, abnormal sensory behaviours such as increased or decreased sensitivity to various sensory inputs are often reported in children with ASD. Tactile hypersensitivity or defensiveness, wherein a benign tactile stimulus appears noxious to the child is most common (Spence et al., 2004). In addition, similar hypersensitivity or hyposensitivity is seen in the visual and auditory domains, with severe behavioural responses to loud noises or atypical visual inspection (i.e., peering at very close proximity). Additional reports also suggest an increased pain threshold among children with ASD, wherein a child may sustain major injury without complaint (Filipek et al., 2000; Charman & Baird, 2002).

In 25-33% of children with ASD there is a period of regression, whereby the child experiences a loss of previously acquired skills, i.e., loss of vocabulary, a reduction in social interaction, and sometimes an increase in repetitive play behaviour. Tuchman and Raplin (1997) report this regression occurring most frequently around the age of 21 months.

At present there is no explanation why this kind of regression occurs in some children and not others (Baird et al., 2003). It has been suggested that regression reflects a sub-group within ASD, with a different aetiology or prognosis from other forms of autism (Rogers & DiLalla, 1990). The Medical Research Council (MRC, 2001) noted that data regarding regression is limited and that it remains unknown if the loss of words that had been acquired earlier is a widely experienced phenomenon among the general population with ASD or whether it has prognostic relevance. In any case, regression of previously acquired skills also can be found in cases of illness following viral encephalitis (Gillberg & Steffenburg, 1987). The phenomenon is also being investigated in relation to acquired aphasia (i.e., language impairment) with epilepsy (Landau-Kleffner Syndrome; Le Couteur et al., 1989). Commonly, regression is considered of significant importance (Baird et al.,

2003) or a ‘red flag’, (Manning-Courtney et al., 2003), if reported by parents during the assessment process. However, it is often difficult to ascertain whether development was truly typical before the regression became apparent (Tuchman, 2003).

#### **4.5 Summary**

The symptoms of ASD, including problems with social relatedness, communication, and restricted interests and repetitive behaviours are now much better understood than they had been in the past. There are, however, a number of related problems such as abnormal sensory behaviours and/or periods of regression that require more detailed examination. The exact causes for ASD remain unclear.

### **5. Risk and protective factors**

While there is no screening instrument that can be used reliably to identify all children with ASD (MRC, 2001), close collaboration between parents and professionals and rapid response to parental concerns is recommended (Baird et al., 2003). However, commonly there are significant delays between the parents’ first recognition that something is different in respect of their child’s development and formal diagnosis (Smith et al., 1994). In many cases, unless parents exhibit distress or proactively discuss their concerns, professionals can be slow to recognize disorders in children or miss them altogether even when signs and symptoms are apparent (Palfrey et al., 1987; Shevell et al., 2001).

#### **5.1 Age of diagnosis**

Until recently, researchers and clinicians thought that core symptoms of autism could not be adequately assessed and a reliable and valid diagnosis not given prior to 6-10 years of age (Ehlers & Gillberg, 1996). Since then, investigators have acknowledged that younger children can be diagnosed (Matson et al., 2007) and that there are long-term benefits for children who receive early diagnosis (Matson et al., 2004a, 2004b; Smith et al., 2000). Today, autism is routinely identified by the age of 3 years (Howlin & Moore, 1997) and can be recognized by 18 months in severe cases (Baird et al., 2000; Baron-Cohen et al., 1996); however, a diagnosis of the broader autism spectrum is less reliable at this age than in older children (Charman & Baird, 2002; Stone et al., 1999). Features that may present during the first 2 years of life include impairments in social interaction, social smile, and facial expressions, ignoring people, poor eye contact, and the lack of appropriate gestures (Adrien et al., 1992), as well as an inability to show or point to and orient to name objects (Osterling & Dawson, 1994).

#### **5.2 Gender, socio-economic, and ethnic factors**

The gender ratio of children with autism is 4:1 (male to female) across the full IQ range (Rutter, 1978), rising to 9:1 among children with Asperger syndrome (Wing, 1981). No epidemiological survey has identified more girls than boys with autism (Fombonne, 2005a). In respect of children with PDD-NOS and intellectual disabilities, the percentage of boys is less dominant. Among children with a profound level of disability, a gender ratio of 2:1 (male to female) is typical (Fombonne, 2003).

Wing (1981) speculated that this gender difference may be due to the fact that boys have an increased susceptibility towards the development of ASD and/or that in girls there is a pre-requisite for more brain involvement before they show symptoms of ASD. However, this suggestion remains untested at present; it also remains possible that ASD is harder to recognise in girls under the current diagnostic criteria, which may be more successful at identifying atypical behaviours in males than females (MRC, 2001).

Following Kanner's (1943) initial observations that children with autism were frequently born to parents of high socio-economic backgrounds, others (Brask, 1972; Lotter, 1966; Treffert, 1970; Wing et al., 1976) confirmed an association between autism and higher social class or parental education level. However, it is likely that these findings reflect a bias in accessing services at that time rather than actual differences in prevalence rates (MRC, 2001; Fombonne, 2003; 2005a). An association between autism and ethnic or immigrant background has been examined (Dyches et al., 2004), however as with social class, the findings are inconclusive and based upon small sample groups (MRC, 2001; Fombonne, 2003; Rutter, 2005).

### **5.3 Medical co-morbidity**

Medical conditions often found in children with ASD include epilepsy, Fragile X syndrome, tuberous sclerosis, cerebral palsy, phenylketonuria, Down's syndrome, congenital rubella, and hearing and visual impairments (Fombonne, 2003; Gillberg & Coleman, 2000). The exact degree of co-morbidity is unclear and is estimated to be between 10% (MRC, 2001) and 33% (Baron-Cohen et al., 1999). It seems that epilepsy rates are relatively high among children with autism and even higher among children who also have severe intellectual disabilities, although no exact figures exist (Gillberg et al., 1991; Fombonne & du Mazaubrun, 1992).

### **5.4 Intellectual impairment**

ASD is often associated with intellectual or learning disability (ID). Clinical diagnosis of ID requires the presence of global intellectual impairment, impairment of adaptive functioning, and onset during childhood (American Association on Mental Retardation, 2002) and is usually reflected in IQ scores of less than 70 (Fombonne, 1997).

The link between ID and autism was established in early descriptions of the condition that suggested that either 4 out of 5 (Wing & Gould, 1979) or 75% (Rutter, 1978) of children with autism had a learning disability. Today, this figure is thought to be lower and estimates suggest that ID is found in 25-40% of children with ASD (Baird et al., 2000; Chakrabarti & Fombonne, 2001). In other words, children with ASD are no longer assumed to have intellectual disabilities as well (Hill, 2004; Matson et al., 2007), in fact individuals with Asperger syndrome usually evidence high levels of intellectual ability (Volkmar, 1998) although they may be significantly impaired in terms of social skills (Dover & Le Couteur, 2007).

In addition, individuals with classic autism and ID often also show language delays, stereotypes, and self-injurious behaviours (Wing, & Gould, 1979), other neuro-developmental conditions, such as attention deficit disorder (ADD) (Goldstein & Schwebach, 2004), specific developmental disorders, such as language impairment,

dyspraxia, and dyslexia (Dover & Le Couteur, 2007), or language disorders, particularly those affecting semantics and pragmatics (Brook & Bowler, 1992; Rapin, 1997).

## **5.5 Psychiatric disorders**

The assessment of co-morbid psychiatric disorders among individuals with ASD is made difficult by usually poor communication skills (Howlin, 1998), literal interpretation of questions (Wing, 1986), concrete thinking (Dykens et al., 1991), or impaired general ability and obsessions (Volkmar & Cohen, 1991), all of which make it difficult to differentiate autistic features from psychiatric symptoms (Wing, 1981; Clarke & Gomez, 1999; Szatmari et al., 1998).

Having said this, some studies have found evidence of increased rates of schizophrenia among individuals with ASD (Volkmar & Cohen, 1991; Clarke & Gomez, 1999; Petty et al., 1984), while others reject this notion (Ghaziuddin et al., 2002; Chung et al., 1990). Depression is diagnosed in 2% of children with ASD (Ghaziuddin et al., 2002) and approximately 30% of individuals with Asperger syndrome (Wing, 1981; Ghaziuddin & Butler, 1998; Ghaziuddin et al., 2002). Other co-morbid psychiatric conditions include compulsive behaviours (Buxbaum et al., 2004), obsessive-compulsive disorder (Bejerot et al., 2001), phobias and anxieties (Matson, & Love, 1990), hyperactivity, tics, and Tourette's syndrome (MRC, 2001), sleep abnormalities, and challenging behaviours (Elia et al., 2000).

## **5.6 Early diagnosis and other protective factors**

One of the main protective factors is the potential to diagnose ASD in very young children and consequently to initiate intervention early. Clearly, the earlier the diagnosis is given and interventions start the better. However, due to limited resources, families usually have to wait for and struggle to obtain a diagnosis. Despite the fact that symptoms of ASD can often be detected in a child as young as 12-18 months of age (Howlin & Asgharian, 1999; Osterling, & Dawson, 1994; Osterling et al., 2002) and can be reliably diagnosed by the age of 30 months (Baird et al., 2000), the average age before a child is formally diagnosed is between 5-6 years of age (Howlin & Moore, 1997). Palfey et al. (1987) found that the identification of ASD was usually delayed to such an extent that the education system rather than the health system identifies approximately 70% of children with ASD.

Howlin and Moore (1997) found that 50% percent of parents reported recognising problems by 2 years of age; half of these children received a diagnosis by the age of 5 years, whilst the remaining children experienced even longer delays and multiple referrals, before a formal diagnosis was made. Services in N.I. are underdeveloped when compared to the rest of the UK (ASD Working Group, 2007), which means that the average waiting time for diagnosis in N.I. varies between 24-26 months (Cassidy & Morgan, 2006).

With regard to children with Asperger syndrome, Jones et al. (2007) found that 60% of parents in N.I. reported that their child was not diagnosed until late primary or post-primary school age (9-11 years), with 58% of parents reporting they were 'not very satisfied' (29%) or 'not at all satisfied' (29%) with the diagnostic process. In addition, 10% of parents sought a private diagnosis because they had become frustrated with waiting times or were not in agreement with the professional opinion.

Problems related to reaching an early diagnosis include failure to recognise symptoms; denial of the problem; failure to get referral; waiting time for appointment; inadequately trained staff for diagnosis; and separate waiting times for each professional group (NAPC, 2003). These problems lead to parental dissatisfaction (Smith & Bryson, 1994) and, for example, Konstantareas (1990) noted that late diagnosis

- could make the problem even more difficult for parents due to uncertainty;
- could result in confusion, hostility, and avoidance of the child;
- prevents speedy access to appropriate early behavioural interventions;
- prevents access to appropriate social and home supports;
- could lead to parents unwittingly reinforcing problem behaviours;
- deprives the family access to the necessary resources and supports.

A positive experience with the diagnostic process has a significant impact on parents' initial reaction to the diagnosis of a developmental disability (Cottrell & Summers, 1990; Leff & Walizer, 1992; Stallard & Lenton, 1992) and obviously, the earlier a child is diagnosed, the sooner parents can come to terms with the diagnosis (Futagi & Yamamoto, 2002) and realise that the problems they faced with their child were not due to their lack of parenting skills (Nissenbaum et al., 2002). Howlin and Moore (1997) found that parents were more satisfied if they received early, clearly defined diagnosis however, 49% of parents remained "not very" or "not at all" satisfied with the diagnostic process.

Apart from the age at diagnosis other important factors include the level of functioning the level of anxiety, mood swings, difficulty making transitions, echolalia, or absence of speech (Rapin, 1997; Norton & Drew, 1994), language skills, inappropriate and embarrassing public behaviour, disruption and destruction in the home, violence and aggression, inappropriate sexual expression, and obsessions with eating and toileting (Gray, 1994), resistance to being held, cuddled, or kissed by parents, and erratic sleep patterns (Hardman et al., 1993). A child's need for 'sameness' and routine behaviour has also been reported as a contributing factor to parents' distress especially if the slightest change in routines results in relentless tantrums (Norton & Drew, 1994).

Few longitudinal studies exist that follow individuals with ASD from childhood to adulthood. Without specific reference to intervening variables, Gillberg (1998) reported normal or near normal social life and accepted functioning at work or school in 5-17% of individuals. However, the single best predictor of outcomes seems to be IQ (Rutter, 1970; Gillberg & Steffenburg, 1987), although language acquisition also seems to be a protective factor for positive psychosocial outcome (Rutter & Lockyer, 1967).

### **5.7 Parenting**

Despite the fact that ASD creates stress for parents (Yirmiya, & Shaked, 2004), a number of studies have documented high levels of appropriate parenting behaviours among parents of children with autism (Siller & Sigman, 2002; Yirmiya, & Sigman, 2001); however, limited financial resources, lack of appropriate services, and insufficient supports can contribute to poor prognosis (Seifer et al., 1992). Furthermore, parents of children with ASD are at significantly higher risk of experiencing psychological difficulties than parents of non-disabled children (Bromley et al., 2004; Fombonne et al., 2001) and parents of children with other disabilities or chronic illnesses (Bouma & Schweitzer, 1990; Kasari & Sigman, 1997; Koegel et al., 1999).



Due to traditional gender roles connected to breadwinning and child-rearing (Gray, 2003) it still seems that having a child with ASD has a greater impact on mothers than on fathers (Sharpley et al., 1997; Seltzer et al., 2001). Although most fathers acknowledge the difficulties that their child's diagnosis presents within the family, they usually claim that this does not affect them personally; this is not true for mothers (Gray, 2003). It may be that fathers view their role as supporting their child to reach financial independence, while the responsibility of caring for a child with autism falls predominantly upon the mother, who as a result, oftentimes experiences significant levels of chronic stress and fatigue and even seeks psychotherapy and/or medication (Gray, 2003).

Good relations between parents are obviously an important protective factor when caring for a child with ASD. However, parenting a child with autism can have detrimental effects on marital relations. Featherstone (1980) found that having a child diagnosed with a disability could produce powerful emotions of shared failure in both parents, reshape the marital and family environment, and create fertile ground for arguments and conflict. Subsequently, parents may separate or divorce emotionally or physically (Piven et al., 1996). Bromley et al. (2004) found that one in three families of children diagnosed with ASD were lone parents. Broach et al. (2003) reported a lower rate of lone parents (17%) among families of children with ASD, but this was still much higher than the national average for the UK of 10%.

### **5.8 Finance and services**

Concern about availability of adequate financial resources in relation to schooling, therapy, and medical services can add stress to families (Rodrigue et al., 1992; Plenis et al., 1988). Sanders and Morgan (1997) observed that because mothers of children with ASD view themselves as primary carers, they oftentimes give up gainful employment outside the home, which obviously adds further financial strain. Gray (2002) confirmed that approximately 50% of mothers stated that the child's autism prevented them from either working at all or restricted their hours and the type of employment available to them.

There is a strong association between parental emotional distress and the degree of unmet service needs (Hare, 2004). Concerns focus mainly on quality of service provision, such as the difficulty in accessing services, limitations in involvement in interventions, services that are not effective in meeting the needs of the child or family, and lack of interagency collaboration (Kohler, 1999). Families who do not have a key worker seem to have significantly more unmet needs, particularly those families who have most problems and fewest resources (Sloper & Turner, 1992).

In the UK, the use of medication plays a limited role in the management and treatment of ASD (PHIS, 2001). However, effects of medication that target specific symptoms have been studied, including serotonergic function aimed at reducing repetitive behaviours and aggression (McDougle et al., 2000; Gordon et al., 1992), inhibition of impulse transmission in dopaminergic neurons aimed at reducing challenging behaviours, and drugs that influence adrenaline and noradrenaline systems aimed at reducing over-activity (Gordon et al., 1992; Jaselskis et al., 1992).

Results are inconclusive and potential benefits and adverse side effects require further research (PHIS, 2001). Importantly, there is concern that pharmacological approaches may be used in place of more effective behavioural interventions (Baron & Cohen et al., 1999;

Lord, & McGee, 2001; Maine Administrators of Service for Children with Disabilities, 2000; Matson et al., 2007; Matson & Minshawi, 2006; MRC, 2001; New York State Department for Health, 1999; Tanguay, 2000).

## **5.9 Family and social functioning**

Psychosocial adjustment of siblings of children with ASD includes feelings of anger, embarrassment, and guilt, as well as protective feelings toward their brother or sister with ASD (Kaminsky & Dewey, 2002), positive self-concept, interpersonal and care-taking skills (Howlin & Yates, 1990), while there seems to be no apparent jealousy or rivalry between the brothers and sisters of children with ASD (Miller, 2001). However, siblings of a child with ASD appear to be more embarrassed in the presence of other children and peers than siblings of children with intellectual disability, e.g., Down syndrome (Roeyers & Mycke, 1995). Howlin and Yates (1990) confirmed that this may be accounted for by specific behaviours of children with ASD that are typically viewed as 'bizarre', noting that most of the problems brought up during support group sessions for siblings of children with ASD, had to do with peers and their reactions. In one of the few comparative investigations of ASD children and their siblings, DeMyer (1979) found that 30% of siblings reported feelings of being neglected and 18% expressed worries and anxieties associated with ASD. Other findings indicate a feeling that sibling needs are secondary to those of the child with ASD, and that more time and attention was given towards the child with ASD (McHale et al., 1984). Levels of loneliness and academic achievement were related to levels of social support from friends (Kaminsky & Dewey, 2002).

Younger, pre-school siblings are particularly vulnerable to feelings of confusion and isolation due to the fact that parents themselves are likely to be in the initial stages of adjustment to the reality of their child's disabilities, resulting in fewer quality interactions with the pre-school, typically developing child (Lobato, 1985). In addition, a relatively high incidence of learning difficulties and language-related problems, such as speech delay or reading and spelling problems has been reported in siblings of children with autism. Some argue that this may be accounted for genetically as sibling may have some of the genes that increase the susceptibility of ASD (Rutter, 2005).

Family context clearly is an important contributor to the quality of sibling relationships (Rivers & Stoneman, 2003). Dunn (1984) suggested that a family's response to stress influences sibling perception of the situation, i.e., if parents react positively to their child with special needs, then the sibling relationship tends to be more positive. In addition, McHale et al. (1984) thought that siblings in larger families seem to adjust better than siblings in smaller families because larger family size was associated with less embarrassment and fewer feelings of burdens for siblings.

Making plans for the future of their child, when they are no longer able to care for him or her themselves, is another important concern for parents. Parents are often pessimistic about their child's future and worry about the possibility of life-long dependency (Piven et al., 1996). Future planning and deciding the appropriate care for their child after their deaths is a stressful activity and has the potential for family conflict (Sanders & Morgan, 1997).

## 5.10 Summary

There are many risk and protective factors faced both by individuals with ASD and their families. Unfortunately, limited research specific to all of Ireland is available. The absence of empirically validated and peer-reviewed research studies investigating these issues in N.I. and R.O.I. contexts may reflect the fact that some service providers and researchers continue to underestimate the challenges faced by individuals with ASD and their families in these communities.

It seems that the more severe a child's ASD symptoms are the greater the degree of parental distress (Hastings et al., 2005). Some parents isolate themselves and their families from social contact with the outside world altogether, or restrict their social life to immediate family members, a few friends, and other parents of children with ASD (Gray, 1992; Piven et al., 1997; Rodrigue et al., 1992). Parents generally are concerned for the well-being of their other children and commonly cite the loss of typical family socialising experiences as one of the worst effects of autism on their families (Gray, 1992; Haeefe & Henggler, 1983).

## 6. Assessment and diagnosis

Although both the DSM-IV (1994) and the ICD-10 (1993) list diagnostic criteria that need to be observed before a diagnosis of ASD can be made, these are not sufficient for a holistic diagnosis and assessment (Manning-Courtney et al., 2003). In the absence of quantifiable biochemical or neurological markers, diagnosis is reliant on clinical decisions based on observations of behaviour and reliable reporting of current and historical information regarding the child (Filipek et al., 2000).

### 6.1 Assessment tools

Assessment includes (1) taking a detailed developmental history from the parents, educators, multi-disciplinary supports and/or therapists (Lord, 1997) as well as (2) directly observing child behaviours, both formally during interview and informally at home, playgroup, and/or school (Pilowsky et al., 1998).

(1) Standardised instruments that rely on parental reports (Eaves & Milner, 1993), include The Gilliam Autism Rating Scale (Gilliam, 1995), The Pervasive Developmental Screening Test-Stage 3, (Siegel, 2001), The Autism Diagnostic Interview-Revised (ADI-R), (Lord et al., 1997), and the Diagnostic Interview for Social and Communication Disorders (DISCO; Leekam et al., 2002). Eaves and Milner (1993) thought that the main advantage of these instruments was probably that they gave parents, teachers and other professionals the opportunity to feel part of the diagnostic process.

(2) Direct observational instruments include The Childhood Autism Rating Scale (Mesibov et al., 1989), The Screening Tool for Autism in Two-Year Olds (Stone et al. 2000), and the Autism Diagnostic Observations Scale-Generic (ADOS-G; Lord et al., 2000). However, Rutter and Schopler (1992) illustrated the considerable variability among clinicians and researchers in their approach to diagnostic classification of autism.

In respect of Asperger syndrome, assessment scales include the Asperger's Syndrome Diagnostic Scale (ASDS; Myles et al., 2001), the Autism Spectrum Screening Questionnaire (ASSQ; Ehlers et al., 1999), the Childhood Asperger Syndrome Test (CAST; Scott et al., 2002), the Gilliam Asperger's Disorder Scale (GADS; Gilliam, 2001), and the Krug Asperger's Disorder Index (KADI; Krug & Arick, 2003). Campbell (2005) concluded that all of these scales demonstrate a number of significant weaknesses, particularly in relation to normative data, and suggested that the KADI was probably the most empirically validated of the available instruments.

## **6.2 Assessment process**

Although assessment and diagnosis are important, in order to inform all those involved with the child of developmental and intellectual impairments, determine family needs, and identify necessary resources (Baird et al., 2003), access to assessment and interventions is not consistent across the United Kingdom and Ireland (Howlin & Moore, 1997). Recent efforts to establish guidance to professionals (NAPC, 2003) addressed issues of consistency during identification, assessment, diagnosis, and access to early interventions (i.e., ABA) for pre-school and primary school aged children with suspected ASD, whilst providing clear and structured recommendations to support this process (Dover & le Couteur, 2007). Most importantly, the National Autism Plan for Children (NAPC, 2003) emphasised that “[p]arental concern about developmental problem should trigger referral for a general developmental assessment (GDA) and not be deferred until the next routine surveillance check” (p. 10).

NAPC (2003) recommended that every effort should be made to provide local assessment and standardised services for children with ASD; that a clear time frame for assessment was made available; that professionals gained knowledge and awareness of autism spectrum disorders through training; that families were actively involved in care planning and procedures; that multi-disciplinary and multi-agency work was efficient; and that national networks were set up. NAPAC outlined clear referral routes for children with suspected ASD that have been integrated into the “The Blueprint for Change” for N.I. (Autism NI, 2006).

## **6.3 Summary**

Confusion and inconsistencies surrounding the diagnostic process for ASD are due to rapid changes in knowledge and understanding of ASD (Stone et al., 1999) and changes in diagnostic criteria that require continuous re-training of clinicians to avoid outdated practices (Heidgerken et al., 2005). Recent efforts to standardise assessment and diagnostic processes and develop systematic guidelines (NAPC, 2003) offer conceptual frameworks that address issues faced by families during the assessment process. Furthermore, comprehensive standardised tools provide clinicians with appropriate protocols. The acknowledgment of the pivotal role played by parents ensures a person-centered approach during assessment and diagnostic procedures.

## **7. Financial impact**

The total aggregated cost for the provisions of care, special education, rehabilitative and sheltered work, day service provisions, and family expenses in the UK for individuals with

ASD is estimated to be approximately £1 billion per year (Järbrink & Knapp, 2001). The estimated individual cost across the lifespan for a person with ASD and additional intellectual disability is £2.94 million per person; for individuals with ASD but without an intellectual disability, the cost is estimated £785,000. Residential and home supports accounted for 70% of the total cost; day service provisions accounted for 14%; and special education provisions accounted for 7% of the total estimated costs (Järbrink & Knapp, 2001).

In fact, most recent figures estimated the annual costs for low-functioning children with ASD living in residential or foster care as between £16,185 and £62,536, and for high-functioning children between £1,214 to £21,090. Where children lived with their families, costs were lower, although informal care by families was not included. Costs for adults included lost employment and were estimated to be between £32,681 and £97,863 per annum, depending where the person lived (i.e., private household, supported living, care home, or hospital). This amounts to total annual costs of ASD in the UK alone of £2.7 billion for children (mostly for services) and £25 billion for adults (for services and lost employment) (Knapp et al., 2007).

Clearly, this financial impact is a significant burden on society and families (Loynes, 2000) that is exaggerated by the shortfall that exists between the costs of bringing up a child with severe disabilities and benefits received (Broach et al., 2003). The total cost of raising a child with a disability is estimated as being approximately three times greater than the cost incurred raising a non-disabled child (Järbrink et al., 2003).

Given an estimated 250% increase in demand for ASD services in the future (Report of Task Group on Autism, 2002), there are potentially two scenarios. First, in the absence of appropriate service planning, and with the implementation of ASD specific services and intervention, services will continue to be reactive to individual needs, thus incurring significantly higher costs trying to address the needs of individuals who were previously unaccounted for and therefore were not included in budgetary estimates. Second, overstretched and under-resourced services will be trying to address the needs of an influx of individuals. This will result inevitably in longer waiting times to access residential, day- and multi-disciplinary services, home supports, and appropriated interventions. This in turn will place greater pressure on parents to become full-time carers of the children, restrict family income, and continue the cycle of frustration and restricted access to appropriate services and interventions. This is a reality that is already being experienced by many families in Ireland.

## **8. Statutory service provisions**

It is impossible to detail in depth all services available for children with ASD and their families (cf. Ives, & Munro, 2002). The following information provides a brief overview of services typically available (Dover & le Couteur, 2007) that either are included in the National Autistic Society's (NAS, UK, 2007) autism services directory (listed under advice and advocacy; assessment and diagnosis; education; health; support groups and training; and events); the R.O.I. 's Local Health Authorities; or the Irish Department of Education and Science list of services. Although not all inclusive, Figure 1 highlights the range of service requirements for children and adults with ASD (adapted with permission from the National Autistic Society, Scotland; NAS, SCOT, 2007).





## 8.1 Northern Ireland health and social services

In N.I., there currently are four Area Boards that are responsible for assessing needs and commissioning services for their respective populations, as well developing policies to meet their objectives. These are

- Eastern Health and Social Services Board
- Northern Health and Social Services Board
- Southern Health and Social Services Board
- Western Health and Social Services Board

Discussions on restructuring indicate that, from 1 April 2008, these four Area Boards may be replaced by the Health and Social Services Authority (HSSA) that will be responsible for overall management of all Health and Personal Social Services. If this happens, the new Authority might be accountable to the Department of Health.

Five Health and Social Care Trusts provide community care and social services commissioned by the Boards. Trusts have already recently been restructured and will remain in place after April 2008. These are

- Belfast Health and Social Care Trust
- South Eastern Health and Social Care Trust
- Northern Health and Social Care Trust
- Southern Health and Social Care Trust
- Western Health and Social Care Trust

The kinds of services provided by Trusts include

- *Statutory medical and social services*, such as hospitals, doctors, health visitors, school nurses, and social workers, are available to the general population.
- *Diagnostic and assessment clinics* for children suspected as meeting the diagnostic criteria for ASD, usually involve a multi-disciplinary team of psychologists, paediatricians, speech and language therapists, and social workers, etc.
- *Early Intervention Teams* (EIT) are multi-disciplinary, usually comprised of paediatricians, psychologists, social workers, speech and language therapists, occupational therapists, physiotherapists, and may include pre-school teachers and playgroups and social work support staff, offering an integrated service to infants and young children, however, they do not offer intensive ABA-based treatment.
- *Child development clinics* assess children, where there are concerns with development, complex disability, socialisation, or communication. These clinics are multi-disciplinary, comprised of medical, nursing, allied health professionals, therapeutic, social work, and other health care staff, and provide treatment and care.
- *Home support services* include home help, domiciliary care, home or family support, or direct payments to help parents organise and pay for their own home support.
- *Respite provision* can be used in crisis situations or can be pre-planned and include out-of-home respite, where the child is cared for in a designated respite unit for short periods of time; in-home respite, where someone comes into the home to provide assistance; home-to-home scheme, where another family volunteer cares for the child on a respite basis; holiday club, where provisions are made for the child to attend social and leisure activities during the holiday period; after-school club, which provides afternoon care in a designated facility.

- *Residential services* usually comprise of large residential units or community-based living (i.e., community group homes), treatment and assessment services.
- *Day service provision* typically includes adult training centres, rehabilitation centres, resource centres, supported and sheltered employment.

Availability of each of these services varies across Trusts. Places usually are limited and allocated on a resource- rather than needs-led basis. There are no statutory services that provide Applied Behaviour Analysis delivered by Board Certified Behavior Analysts (BCBA, cf. 9.8) for individuals diagnosed with ASD.

## **8.2 Northern Ireland education services**

Central administration of education in N.I. is the responsibility of the Department of Education for N.I. (DENI), including pre-school, primary, post-primary and special education; the youth service; community relations within and between schools; and teacher education and salaries. Higher and further education is the responsibility of the Department for Employment and Learning (DELNI).

Locally, education presently is under the jurisdiction of one of the five Education and Library Boards whose role it is to ensure high quality education and youth and library support services. The five Boards are

- Belfast Education & Library Board
- North Eastern Education & Library Board
- South Eastern Education & Library Board
- Southern Education & Library Board
- Western Education & Library Board

The Boards are supported by the C2k Classroom 2000 initiative that is responsible for the provision of information and communications technology (ICT) to all schools in N.I..

## **8.3 Republic of Ireland service provisions**

In the R.O.I., the Health Services Executive is responsible for specialised pre-schools for children with intellectual disabilities and the Department of Education and Science offers school level educational services. Facilities include nursery provisions (statutory and voluntary), pre-schools, special pre-schools for intellectual disability, mainstream schools, special class mainstream school, special class primary level, special class secondary level, child education and development centres (programmes for children with severe or profound intellectual disabilities). Some educational authorities also provide autism specific classes in mainstream schools at primary level.

Special Education Needs Coordinators (SENCO-N.I.) or Special Education Needs Organisers (SENO – R.O.I.) are responsible for co-ordinating and facilitating delivery of educational services to children with disabilities at local level.

## **8.4 Financial support**

Parents of children with ASD are provided with financial supports for the care of their child, typically including transport costs, medical cards, disability allowance, domiciliary



care allowance, disability allowance, respite care grant (i.e., direct payments), and mobility. This does not include cost incurred for therapeutic support or intervention.

### **8.5 Monitoring procedures**

A number of mechanisms are in place to monitor service delivery. These include Special Education Needs Statement (SENS); Individual Education Plan (IEP); and Person Centred Plan (PCP).

#### *Special Education Needs Statement (SENS)*

In N.I., a SENS is a legally binding document within which the special educational needs of the child are set out (Department of Education, 2007). Education and Library Boards (ELB) and schools and other relevant bodies have a statutory duty, under the Education (N.I.) Order 1996 and 1998, Article 4, amended by Special Educational Needs and Disability (N.I.) Order 2005, to demonstrate that their arrangements meet individual needs.

The Education (N.I.) Order (1996/1998) in its *Code of Practice for the Identification and Assessment of Special Education Needs* (para 4.34) identifies that ELB have a duty to ensure that children with SENS are educated in mainstream schools provided that 3 conditions are met: the placement must be appropriate to the child's needs, it must be in the interest of children already in the school; and it must make use of ELB resources efficiently. Parental preferences must also be taken into consideration. These conditions should govern the choice of special school that a child attends (Report of the Task Group on Autism, 2002).

Under the Education (Special Educational Needs) Regulations (N.I.) 2005, Statutory Rule No. 384, ELB have to fulfil their obligations within six weeks of a parent (or responsible body) seeking an assessment. In addition, Section 11 (time limits and prescribed information relating to assessment) ensures that "where under Article 15(4) or 20A(7) a board has given notice to the child's parent of its decision to make an assessment it shall complete that assessment within 10 weeks beginning with the date on which such notice was given" (Special Education Needs Statement, 2007).

#### *Individual Education Plan (IEP)*

An IEP is a teaching and planning tool that outlines additions to, or differentiations in the curriculum specifically tailored for an individual child. An IEP should be clearly written and identify three or four individual targets for the child in question. The key areas addressed in an IEP are communication, literacy, mathematics, general classroom behaviour, and social skills. For children with ASD the key focus of the IEP should be on the development of communication, social skills and understanding, and behavioural flexibility. The UK Department of Education and Skills (2002) recommends that an IEP should be prepared with full parental participation. Furthermore, IEPs should be based directly on evidence gathered during the SENS process and include a family or child/adult relationship aspect. The ultimate aim of an IEP is to compensate for the needs that arise from the child's disability in order to allow the child to be educated in the least restrictive setting. Ultimately, the IEP sets out any activities that are different or additional to general mainstream education, sets short-term objectives and outlines strategies of how to achieve these aims. It is based on the SENS and must be the focus of planning, teaching, resource allocation, and review (Department of Education and Skills, 2002).

An effective IEP includes a brief child profile, incorporating strengths as well as challenges; baseline measures of performance; measurable short-term goals; a timeline with dates for when each target is to be achieved; and an outline of overall general strategies to be utilised, including an indication of which support services are required to allow the child to be included with mainstream peers. IEPs need to be available to all staff working with the child as well as to the parents of the child (Report of Task Force on Autism, 2001).

#### *Person Centred Plan (PCP)*

A PCP is written in order to assist individuals in the creation of a personalised image of a desired future (Autism Society Michigan, 2007). Person centred planning is a process whereby persons with disabilities, with the support of families, direct the planning and allocation of resources to meet their own life vision and goals. The PCP should be based on community presence, community participation, choice, respect, and competence. The individual, the multi-disciplinary support team, as well as the parents should review the PCP at least once a year (Bureau of Developmental Disabilities Services, 2006).

### **8.6 Future service provisions**

A number of initiatives have been taken to ensure future service provision for people with ASD. For example, the All-Party Parliamentary Group on Autism (APPGA) was set up with the following aim:

"To raise awareness of issues affecting people with autism and Asperger's syndrome, their families and carers; to raise Parliamentary awareness of autism; to campaign for changes to government policy to benefit people with autism and Asperger's Syndrome and improve diagnosis or, support for, people with autism and Asperger's syndrome." (APPGA, 2003)

In order to achieve these goals the APPGA concentrated on four areas of development:

- *Training*: There will be a statutory requirement that all professionals or auxiliary staff working with people with autism will have received autism awareness and job specific training in autism prior to commencing their employment.
- *Research*: Research into the causes, costs and effective interventions for autism will be prioritised and facilitated by Government agencies.
- *Service provision*: A named senior manager in every local authority will be responsible for the commissioning and delivery of services for both children and adults with autism.
- *Tracking and planning services*: Compatible databases to record cases of autism spectrum disorders will be set up for all agencies at a local and national level in order to monitor prevalence and plan effectively for future services.

Between now and 2013, the APPGA will focus on the following:

- *Diagnosis and family support*: Autism-specific multi-agency diagnostic and assessment teams will be established in every local area, able to provide accurate and sensitive information on autism and families.

- *Early intervention, primary and secondary education:* All children receiving diagnosis of an ASD will be offered a prompt and appropriate early intervention based on best available evidence.
- *Medical care and interventions:* Physiological and other symptoms often associated with autism, for example sleep disorders, sensory dysfunction or gastrointestinal disorders, will be widely recognised and people with autism will receive medical interventions appropriate to their needs.
- *Respite provisions/short breaks:* All families of children with autism and parents or other carers living with adults with autism will be entitled to a minimum of four weeks respite annually.
- *Mental health:* People with autism will become automatically eligible for preventative mental health services after diagnosis, tailored to their needs and developed in line with an autism person centred approach (APPGA, 2003).

In 2006, the *Mental Health and Learning Disability Review* (Bamford & McClelland, 2006) recommended that a “comprehensive needs assessment of people with ASD and their families should be completed as a priority” (p.1).

## **8.7 Early intervention**

Early intervention aims to reduce and/or alleviate the skills differential between children with ASD and their typically developing peers (Hurth et al., 1999; NAPC, 2003; Prizant & Rubin, 1999; Woods & Wetherby, 2003), with the aim that “children could be placed on a normative developmental trajectory and thus continue to show optimal development after early intervention ends” (Ramey & Ramey, 1998, p. 113). During a so-called “zone of modifiability” success is determined by the timing, intensity, and appropriateness of treatment. Treatment delivered directly to children produces better outcomes than treatment that is solely delivered to the caregivers (Ramey & Ramey, 1999).

Numerous studies examining commonly used treatment approaches confirm the importance of early diagnosis and comprehensive early intervention (Dawson et al., 2000; Kasari, 2002; Wolery & Garfinkle, 2002; Zachor et al., 2007). Over the past 40 years considerable empirical evidence has accumulated showing that early intensive ABA-based interventions (cf. 9.4) produce large and lasting functional improvements (Howard et al., 2005; Green, 1996; Maine Administrators of Service for Children with Disabilities, 2000; New York State Department for Health, 1999; Remington et al., 2007; Matson, 2007; Matson & Minshawi, 2006).

## **8.8 Summary**

While on the surface statutory social and educational service provision in N.I. and in R.O.I. appears comprehensive and well organised, financial support or specialist intervention resources are not available. Monitoring provisions are made by way of SENS, IEP, and PCP. Initiatives for the establishment of a co-ordinated approach, such as the setting up of the All-Party Parliamentary Group on Autism in 2000 have been taken and long-term improvements have been promised by 2013. The review by Bamford and McClelland (2006) recommended a comprehensive needs assessment and prioritisation of new funding. There is ample evidence that these initiatives should be underpinned by the science of applied behaviour analysis.

## 9. Behaviour Analysis

Behaviour analysis is a distinct science and profession with a knowledge base that

“includes the full spectrum of learning theories, human development, biological bases of behavior, cognitive aspects of behavior, affective aspects of behavior, psychopathology, principles of measurement, ethics, clinical decision making, ethnic and cultural diversity issues, research methods, and group and single-subject experimental designs. Behavioral psychology is especially also concerned with how the various behavioral, cognitive, affective, biological, and social factors interact and impact each other.” (American Psychological Association, 2007)

Like most other sciences, behaviour analysis encapsulates three distinct but related fields (Cooper et al., 2007):

1. Philosophy of the science: *Behaviourism*.
2. Basic experimental research: *Experimental analysis of behaviour*.
3. Applied technology: *Applied behaviour analysis* (ABA).

### 9.1 Behaviourism: The philosophy of the science of behaviour

In behaviour analysis, behaviour is defined as anything a person does (Reese et al., 1978). Behaviour can have one or more dimensions, such as frequency, duration, and/or latency; can be overt (public) or covert (private); can be observed and recorded by one (self) or more persons; and is lawful, in as much as it is influenced by environmental events (Miltenberger, 2004; Skinner, 1976).

“The key point of behaviorism is that what people do can be understood. Traditionally, both the layperson and psychologist have tried to understand behavior by seeing it as an outcome of what we think, what we feel, what we want, what we calculate, and etcetera. But we don’t have to think about behavior that way. We could look upon it as a process that occurs in its own right and has its own causes. And those causes are very often found in the external environment.” (Cooper et al., 2007, p. 15)

One of the main advantages of defining behaviour as ‘anything a person does’, apart from being inherently a holistic perspective, is the way that it permits ‘private behaviour’ (e.g., thinking (i.e., cognitions) and feelings (i.e., emotions) to be considered when developing explanations. Because private behaviour is included in the overall definition of behaviour, it is regarded as part of the phenomenon that is being analysed rather than as something to be kept separate from other kinds of behaviour that are public (motor movements and verbal behaviour). The following example illustrates this point.

“A British statesman recently asserted that the key to crime in the streets was “frustration.” Young people mug and rob because they feel frustrated. But why do they feel frustrated? One reason may be that many of them are unemployed, either because they do not have the education needed to get jobs or because jobs are not available. To solve the problem of street crime, therefore, we must change the schools and the economy. But what role is played in all this by frustration? Is it the case that when one cannot get a job one feels frustrated and that when one feels

frustrated one mugs and robs, or is it simply the case that when one cannot earn money, one is more likely to steal it—and possibly to experience a bodily condition called frustration?” (Skinner, 1977, p. 4).

This example draws attention to problems created by ordinary language in the analysis of behaviour.

“In ordinary conversation we readily say that a person is mean, kind, thoughtful, and the like. We readily attribute episodes of conduct to a person's intelligence, anxiety, personality, and so forth. This manner of talking does not puzzle us. On the contrary, it informs us. Even so, ordinary psychology usually remains intuitive and unreflected” (Lee, 1988, p. 124).

It is the unreflected nature of ordinary language that concerns the philosophy behind behaviour analysis. Obviously, someone's body can change in such a way that their ordinary language leads them to label this change as ‘feeling frustrated’ (private behaviour). But when the scientific analysis is taken further the question arises: What caused this bodily state? The state is not caused by the frustration itself because the ‘frustration’ is the bodily state and therefore cannot cause itself. Clearly, bodily states like frustration appear only under certain conditions. Since many of the events that must be taken into account in explaining behaviour are associated with bodily states that can be felt, what is felt may serve as a clue to the circumstances responsible for it, but the feelings are not these circumstances and cannot replace them as causes (Skinner, 1977).

This line of argument becomes particularly important when used in relation to children with ASD. A child who behaves in certain ways (e.g., makes no social contact, engages in repetitive, self-stimulatory behaviour, etc.) is typically said to *have* ASD. Frequently, ASD is referred to as the reason (i.e., cause or explanation) for the said behaviours; “he does this because he *has* ASD”. In reality though, the term ASD is used to summarise, purely in a descriptive way, the constellation of behaviours that are presented. Technically, the term ASD is merely a ‘summary label’ (Grant & Evans, 1994) for the full range of the child's behaviours, not the cause of them. Theoretically (and practically), if the range of behaviours that lead to the descriptive label ASD were changed, a different label would have to be used. The extent to which behaviours can be changed is a question that can be answered best by practical scientific exploration.

The forefathers of modern behaviour analysis, American psychologists Edward Lee Thorndike (1874-1949) and John Broadus Watson (1878-1958) stated that psychology should to be viewed as a natural science that includes systematic and direct observations of the interplay between environmental stimuli and behavioural responses (Todd & Morris 1994). By so doing they discovered that behaviour was in fact predictable, lawful, and effected by stimulation from the environment, rather than random and subject to unknown forces, as previously thought.

Without a doubt the most influential behaviour analyst and the one credited with coining the term ‘behaviour analysis’ was Burrhus Frederick Skinner (1904-1990). In *The Behavior of Organisms* (1938) he outlined his vision of the possibility of an experimental analysis of behaviour. Throughout the course of his career he drew attention to the limitations of S-R psychology (a term often used to refer to early behavioural research) and introduced the concept of the 3-term contingency when he found that events occurring in

the environment before a behaviour (antecedents) as well as events occurring in the environment after that behaviour (consequences) influenced the future probability of the behaviour. His contribution to the science and philosophy of behaviour analysis includes experimental as well as applied fields (Skinner, 1965; 1969; 1972; 1976).

## **9.2 Experimental analysis of behaviour**

The experimental analysis of behaviour has led to the discovery of principles of behaviour. For example, respondent (or classical) conditioning is a process by which a stimulus comes to elicit responses that would not have occurred prior to conditioning (Cooper et al., 2007). Respondent conditioning can explain the development of phobias, or prejudice, or tastes aversions. It has also been shown to be effective in trials to suppress the immune system in chemotherapy and recent experiments have explored whether it can be used to boost the immune system to help fight cancer (Chance, 2003).

While respondent conditioning procedures can be used to examine the nature of inherited reflexes, operant conditioning procedures are used to examine the variety of ways that voluntary behaviour is influenced. Experiments measure changes in behaviour when certain antecedent stimuli are present, when certain consequences are presented, and/or when special relations are arranged between antecedents and consequences. The abiding concern throughout all of this research is to extend our understanding of how we are influenced by, and in turn influence, the world in which we live (Bandura et al., 1963; Cooper et al., 2007; Glenn et al., 1992; Sidman, 1994). The natural laws of behaviour that have been uncovered are generally referred to as ‘principles of behaviour’.

## **9.3 Applied behaviour analysis (ABA)**

“Applied Behavior Analysis is the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for *behavior change*.” (Cooper et al., 2007, p. 20)

Many lay people as well as many professionals think that the pioneering work of Lovaas (1987) was the first endorsement of the application of behavioural principles to the treatment of people diagnosed with ASD. In truth, one of the first studies of the application of experimental findings to human behaviour showed that a profoundly intellectually impaired catatonic individual could be taught using operant conditioning procedures (Fuller, 1949). During the 1950s and 1960s, operant procedures were used to benefit children (Azrin & Lindsley, 1956; Baer, 1960; Bijou, 1957), adults (Goldiamond, 1965; Wolpe, 1969), individuals with learning disabilities (Fuller, 1949; Wolf et al., 1964), and individuals with mental illness (Ayllon & Azrin, 1964; Ayllon & Michael, 1959).

Initially, principles of behaviour were applied in a variety of settings through the use of contingent verbal praise (Hall et al., 1968), token economies (Birnbrauer et al., 1965), curriculum design (Becker et al., 1975), and programmed instruction (Bijou et al., 1966; Markle, 1964). ABA was first adopted for individuals with autism in the early 1960’s (Wolf et al., 1964; Matson et al., 1996).

Throughout the history of this science, terms including behaviour modification, behaviour management, behaviour therapy, contingency management, positive approaches, operant or

Skinnerian psychology, or the ‘Lovaas’ approach have been used (Walsh, 1997). As the science progressed from its early roots, the formal definition of ABA abandoned these terms and provided researchers with definitive terminology (Baer et al., 1968). The establishment of the Journal of Applied Behaviour Analysis (JABA) supplied a key outlet to publish applied scientific findings.

ABA adheres to seven basic principles of being applied, behavioural, analytic, technological, conceptually systematic, effective, and capable of generalised outcomes (Bear et al., 1968; Cooper et al., 2007):

1. *Applied*, i.e., brings improvements and change in socially relevant behaviours that bring enrichment to individuals within the context of their social environments;
2. *Behavioural*, i.e., conducted within the scientific framework and philosophy of behaviour analysis focussing on changes in behaviour within a specifiable context;
3. *Analytic*, i.e., focus on quantifiable functional relationships between research design and implementation and change in target behaviour;
4. *Technological*, i.e., use replicable procedures;
5. *Conceptually systematic*, i.e., reflectively linking experimental procedures to applied settings and detailing relationships between procedures and scientific principles;
6. *Effective*, i.e., achieve measurable changes in socially relevant target behaviours (not merely based on statistical significance),
7. *Generality*, i.e., changes have to last across time and in environments that differ from original treatment environments. (p.16)

In addition ABA is accountable, public, doable, empowering, optimistic (Heward, 2005) and more effective than other approaches, such as eclectic treatments (Howard et al., 2005). ABA is not limited to specific strategies or a limited range of target behaviours. Aversive methods are avoided in favour of interventions based on functional assessment and positive reinforcement (Buchanan et al., 2006).

**Table IV: ABA: Areas of application.**

Researcher	Area
Iwata et al., 1982/1994	Intellectual disabilities
Kazdin, 1982; Bellack & Hersen, 1993	Mental health
O’Neil & Gardner, 1983	Rehabilitation
Cope & Allred, 1991; Geller & Hahn, 1984	Community psychology
Hersen et al., 1991	Clinical psychology
Mawhinney, 1999	Business and industry
Yates, 1985	Self management
Watson & Gresham, 1998	Child management
Brobst & Ward, 2002	Sports psychology
Blumenthal & McKee, 1986	Health related behaviours
Gallagher & Keenan, 2000	Gerontology
O’Reilly & Dillenburger, 1997	Conduct disorders
Neef et al., 2005	ADHD

See also Cambridge Center for Behavioral Studies (2007).



Evidently, ‘ABA is not a therapy for autism’ (Chiesa, 2005). It is the science behind a wide range of techniques that are used to help a wide range of people with a wide range of behaviours, autism being one of them (Table IV shows some other examples).

#### 9.4 Applied Behaviour Analysis and ASD

Goin-Kochel et al. (2007) point out that typically, parents try 7-9 different therapies for their child with ASD. In order to short-circuit this process, the onus is on professionals to correctly inform parents on available empirically validated interventions (PEAT, 2007). The scientific method is empirically validated for the education and treatment of individuals diagnosed with ASD (Lockshin et al., 2004; Manning-Courtney et al., 2003). More than 19,000 papers have been published using ABA within a variety of areas, including well over 500 studies concentrating on children with ASD (Anderson & Romanczyk, 1999).

“To date, enough behaviourally oriented Early Intensive Behavioral Interventions (i.e., teaching methods based upon ABA) have been conducted to suggest that not only is the approach effective, but as a congregate group of learning based methods, it stands alone as the only effective treatment(s) for young children with ASD.” (Matson, 2007, p. 111)



Figure 2: Example of a category mistake when the science of ABA is incorrectly labelled as merely one of a number of treatments for autism (©Mickey Keenan).



Although Discrete Trail Training (DTT), popularised by Lovaas (1987), is a prominent application of behaviour analysis in the treatment of ASD, this is not the only method used within ABA with these children. Other methods include the Picture Exchange Communication System (PECS), Verbal Behaviour Analysis (VBA), Precision Teaching, generalisation and skill maintenance training, prompting and prompt fading, imitation and instruction, aggression replacement training, shaping, chaining, differential reinforcement, incidental teaching, extinction, and others (Green, 1996; McGee et al., 1999).

Often, however, ABA is misunderstood as simply one of a number of treatments for autism. This mistake is shown in Figure 2 where people seeking services are being asked to select ABA, or Lovaas, or VBA, etc.. But it is a science, and it has pioneered single-case designs for individualising treatment programmes (Johnston & Pennypacker, 1993).

Figure 3 shows how the shelves should have been labelled. ABA is the science that underpins various methods of application. This corrected picture now raises an important issue. If parents and professionals are misinformed about the science of behaviour analysis, then it is likely they will misunderstand what is required in terms of professional training.



**Figure 3: This picture shows a number of ways that autism has been addressed within the science of ABA (©Mickey Keenan).**

Of course, it also raises an ethical issue. Since ABA is a science it cannot be ‘sold’ because it inherently belongs to everyone, much like biology, chemistry, or physics. What is available for purchase are the services of people who are educated in the science, much like the services of medical doctors or pharmacists can be acquired. Just as medical doctors and pharmacists require thorough accredited training, so do behaviour analysts (cf. 9.8).

These training and accreditation requirements are reflected in the ethical guidelines of professional bodies. The British Psychological Society (BPS), for example, requires professional psychologists to recognised the limits of their competence, and to

- (ii) Practice within the boundaries of their competence;
- (iii) Remain abreast of scientific, ethical, and legal innovations germane to their professional activities, with further sensitivity to ongoing developments in the broader social, political and organisational contexts in which they work;
- (iv) Seek consultation and supervision when indicated, particularly as circumstances begin to challenge their scientific or professional expertise;
- (v) Engage in additional areas of professional activity only after obtaining the knowledge, skill, training, education, and experience necessary for competent functioning;
- (vi) Remain aware of and acknowledge the limits of their methods, as well as the limits of the conclusions that may be derived from such methods under different circumstances and for different purposes; and
- (vii) Strive to ensure that those working under their direct supervision also comply with each of the requirements of this Standard and that they are not required to work beyond the limits of their competence. (BPS, 2006, p.15)

## **9.5 Empirical evidence**

The effectiveness of using the science of behaviour analysis to help individuals with ASD has been documented since the early 1960s (Wolf et al., 1964). However, it was not until the 1980's, in an era when ASD was viewed as largely untreatable (DeMeyer et al., 1974), that Lovaas (1987) documented substantial improvements in all, and near normal functioning in over 47%, of the 19 children who received comprehensive, intensive (40 hours per week), long lasting (at least 2 years), early (starting before 3<sup>rd</sup>, or at the latest 4<sup>th</sup>, birthday) behaviour analytic intervention. The control group of children who received either non-intensive (10 hrs per week) behaviour analytic treatment or eclectic community services did not achieve similar gains. Gains in the intensive treatment group were maintained for 8 of the 9 children at follow-up, when the children averaged thirteen years of age and had been out of treatment for three to nine years (McEachin et al., 1993). Similar results were found in replication studies in the USA (Cohen et al., 2006) and the UK (Remington et al., 2007).

Other studies documenting the efficiency of intensive behaviour analytic interventions were either centre-based (Eikeseth et al., 2002; Harris et al., 1991), home-based (Birnbauer & Leach, 1993; Sheinkopf, & Siegel, 1998; Smith et al., 2000; Weiss, 1999), or other (Anderson et al., 1987; Stahmer & Ingersoll, 2004; Weiss, 1999) and indicated that cognitive functioning, language skills (Harris et al., 1991), and academic performance improved to or exceeded normal levels for many of the children who had received at least 2 years early intensive behaviour analytic treatment (Anderson et al., 1987; Green, 1996; Remington et al., 2007; Smith et al., 2000; Sallows, & Graupner, 2005; Weiss, 1999). Interested readers are referred to Larsson (2005) who supplies 32 pages of listed references on the effectiveness of ABA (cf. Appendix 5). Information provided by the Department of Education for N.I. (Letter dated 26<sup>th</sup> Sept, 2006) under the Freedom of Information Act indicated that they could not supply references for published research showing an eclectic approach to be either as effective or more effective than ABA.

## **9.6 Parental experiences**

Parents who deliver home-based ABA programmes report higher levels of satisfaction and reduced stress levels compared to parents who do not use intensive behaviour analytic intervention (Anderson et al., 1987; Birnbrauer & Leach, 1993; Dillenburger et al., 2004; Smith et al., 2000). Parents who avail of school-based ABA provision for their children are satisfied that their children's needs are met; IEPs are provided; a specific approach to teaching their children is adopted; the school day is not too long; staff know impact of the triad of impairment on learning and teaching; one-to-one attention is provided; their children are respected; staff have good understanding of their children's disability; there are good home-centre links; staff receive specialist training in ABA; and other schools would not meet their children's needs (National Development Plan, 2006).

## **9.7 Cost-benefit analysis**

Some have stated that in purely financial terms intensive early ABA is expensive (approx £20,000 pa; CBC News, 2007), however this cost is incurred only where ABA is not provided by the education system and parents have to employ ABA supervisors and home therapists. In Canada and the USA for example, many provincial medical plans and other insurances cover the costs (CBC News, 2007; Department of Defence, 2007), however in the UK and Ireland parents mainly pay themselves.

In contrast, local authority spend in the UK on special education last year alone was in the region of £4.1 billion (Education and Skills Committee, 2006). Individually (e.g., for a child with communication disabilities), the Audit Commission estimated that £42,243 would have to be spent on non-ABA interventions. Without effective early intervention the total cost to the taxpayer for a child with communication disabilities at age 16 was estimated to be £153,687 (Bynner & Parsons, 1997). The figure for children with ASD is similar; early ABA-based intervention could save £150,000 during the first 15 years of life (PEACH, 1997).

Clearly, if local authority staff were qualified to deliver ABA-based early intervention, there could be even more substantial savings. Additional savings at a ratio of over 4:1 (i.e., £4 benefit for every £1 spent; Lynch, 2005) could be made after the first two years of an intensive programme (Maurice et al., 1996). Due to reduced dependence on health care provisions, early intensive ABA could save the taxpayer £1,000,000 to £2,000,000 across an adult life span (i.e., 59 years; PEACH, 1997). In the USA, cost-benefit analysis showed similar savings, in the region of US \$200,000 per child by the age of 22 years and US \$1,000,000 by the age of 55 years (Jacobson et al., 1998). The lifelong cost associated with providing long term, residential and/or day care services for children who have not benefited from ABA runs into millions (Birnbrauer & Leach, 1993).

## **9.8 Professional regulation**

As mentioned earlier, ABA is a science and a profession. Professionals in behaviour analysis are certified and regulated by the Behavior Analysis Certification Board (BACB, 2007). In the USA, professional certification has been available on a state level for a long time and was nationally recognised nearly 10 years ago.

“While the states of Florida, Oklahoma, Texas, California, Pennsylvania, and New York each had behavior analyst certification programs, these states ceased their state-level certification efforts after the introduction of a nationally recognized certification process by the BACB in 1998.” (Department of Defence, 2007, p. 11)

Increasingly, BACB certification is recognised by providers as the required qualification: “these are the only ABA therapists currently authorized as TRICARE providers of ABA services” (Department of Defence, 2007).

There are two levels of certification:

*Board Certified Behavior Analysts (BCBA)* must have at least Masters degree level training in behaviour analysis as well as 1500 hours supervised independent fieldwork experience prior to taking a rigorous 4-hour exam.

*Board Certified Associate Behavior Analysts (BCABA)* (NB: as of January 2009, Board Certified assistant Behavior Analysts; BCaBA) must have at least Bachelor degree level training in behaviour analysis and 135 hours supervised independent fieldwork experience prior to taking the exam and must be supervised by a BCBA afterwards.

The Behavior Analysis Certification Board is endorsed but independent of the Association for Behaviour Analysis International ([www.abainternational.org](http://www.abainternational.org)). In addition, the National Council for Certifying Agencies in Washington, DC which is the accreditation body of the National Organization for Competency Assurance ([www.noca.org](http://www.noca.org)) recently accredited BCBA and BCABA programs. The Autism Special Interest Group of the Association for Behaviour Analysis provides consumer guidelines that cover general consideration in choosing a director of ABA services, such as requirements for qualification and training (Autism Special Interest Group, 2007).

## **9.9 ABA in Ireland**

In the R.O.I. there are over a dozen ABA-based schools, and “by the start of 2005 over 250 children are learning through this methodology in a school environment, and in excess of 275 people will be in full time employment” (IAA, 2005). There are 15 BCBAs and 27 BCABAs. Three Universities offer accredited training for BCBAs (Galway; Limerick; Maynooth) and 3 Universities offer accredited training for BCABA (Galway; Limerick; Trinity College Dublin) (BACB, 2007).

The Report of the Task Force on Autism (2001), commissioned by the Irish Minister for Education and Science, reviewed the current range of educational provision and support, assessed the adequacy of these services, and submitted recommendations for the development of services. ABA was recommended as one of the two main approaches and the skilled use of ABA by professionally qualified behaviour analysts was endorsed. ABA training was recommended for teachers and the systematic recording of the child’s achievements inherent to ABA programmes hailed as an “important exemplar to be followed for all planned interventions” (p. 107).

In N.I. there are no dedicated ABA schools for children with ASD. One non-for-profit charity run by parents (Parents’ Education as Autism Therapists, PEAT) and a business (Centre for Early Autism Treatment, CEAT) provide ABA home-based programmes. One non-for-profit organisation, also run by parents, is offering pre-school education (STARS

in Kilrea). One ABA-based classroom of 6 children (Special Provision for the Education of Autistic Children, SPEAC) and four Education and Library Board (ELB) staff who recently became Board Certified Associate Behavior Analysts (BCABA) provide school-based support. In addition, a number of professionals have taken short courses provided by the Institute for Applied Behaviour Analysis (IABA) or are receiving in-service training through one or two day courses. In 2006, the University of Ulster began a Masters in Behaviour Analysis that is accredited by BACB and leads to eligibility to take the BCBA exam. At present there are 4 BCBAs (2 from the University of Ulster and 1 from Queen's University Belfast) and 5 BCABAs in N.I. (4 ELB and 1 CEAT).

The Report of the Task Group on Autism (2002) was commissioned by the Department of Education (N.I.) to make recommendations on educational provisions for children and young people with ASD. The report recognised a child's right to effective educational provision from the point of diagnosis although it recognised that when parents seek support for ABA, Education Boards are "dependent on external providers and have not taken steps as yet to become self-sufficient in this respect" (p. 37).

Unfortunately, despite numerous requests from suitably qualified ABA professionals, the failure to include ABA professionals in the writing of the Report of the Task Group on Autism in N.I. and in the Report of the Task Force on Autism in the R.O.I. has led to inaccuracies in the reports with regard to ABA (see PEAT's response to the N. Ireland report at [www.peatni.org](http://www.peatni.org)) and similar inaccuracies appear repeatedly in reports that do not include ABA professionals (e.g., McConkey et al., 2007). By contrast, in order to avoid inaccuracies from the outset, international reports from the USA (Department of Defence, 2007) or Canada (Perry & Condillac, 2003) included ABA professionals on their research and writing teams, or put their draft report out for wide consultation and subsequently put out a tender for a full review of the literature on ABA and ASD (New Zealand; Ministry of Health and Ministry of Education, 2007).

Despite ample evidence regarding the effectiveness and international endorsement of the science of behaviour analysis, to date around €20 million has been spent by the taxpayer in R.O.I. alone fighting parents in the courts to stop them accessing ABA for their children. It is unknown what has been spent in N.I. but the figure is likely to be similar if not larger.

## **9.10 Summary**

Behaviour analysis shares the philosophy of science with other natural sciences. When experimental basic research is sensitively applied to the human condition it yields powerful and positive results. Today ABA is applied to a wide range of human problems and when applied to the area of ASD has proven effective, socially valid, and cost effective. Behaviour analysts are professionally regulated and certified through the Behaviour Analysis Certification Board. ABA was introduced to N.I. in 1997 through the initiative of a small group of parents and professionals (PEAT), who collaborated in setting up the first of a dozen ABA-based schools in R.O.I. a couple of years later (cf. Smyth, de Salvo, & Ardif, 2005). There are still no ABA-based schools in N.I..

## 10. Methodology

### 10.1 Participants

#### Parents/carers

95 parents and carers participated, including 91 parents/carers who had one child diagnosed with ASD, 3 mothers who had two children diagnosed with ASD, and one mother who had 3 children diagnosed with ASD. 69 (73%) parents/carers resided in N.I. and the remaining 26 (27%) resided in the R.O.I. 87 (91%) females (64 from N.I. and 23 from R.O.I.) and 8 (9%) males (5 from N.I. and 3 from R.O.I.) took part; their mean age was 40 years.

Most of the parents/carers (n=84; 88%) were members of an ASD charity. 61 of N.I. parents/carers were members of Asperger Network Group, Autism NI, Centre for Early Autism Treatment (CEAT), National Autistic Society (NAS), and Parents' Education as Autism Therapists (PEAT), and Ski Ability. In the R.O.I., 23 parents/carers were members of Kilbarrack, North County Dublin (ABACAS), Comprehensive Application of Behaviour Analysis to Schooling (CABAS), Gra Autism Parents Group (GRA); Irish Autism Alliance (IAA), Laois Offaly Families for Autism (LOFFA), and Saplings Model of Education.

#### *Relationship with Child*

84 (88%) participants were mothers, 8 (9%) were fathers, 2 (2%) were foster parents, and 1 (1%) was a grandparent. 92 (97%) of the participants were primary caregivers for the child/ren; in the remaining 3 cases fathers responded although they did not consider themselves primary care givers.

80 (84%) respondents belonged to two-parent families, 55 in N.I. and 25 in R.O.I.; 15 (16%) participants constituted one-parent families, 14 in N.I. and 1 in R.O.I.. Table 1 reflects the marital status of participants.

**Table 1: Marital status of participants.**

	<b>n</b>	<b>N.I.</b>	<b>R.O.I.</b>
Married/cohabiting	81 (86%)	56 (81%)	25 (96%)
Single	6 (6%)	6 (9%)	-
Divorced	6 (6%)	5 (8%)	1 (4%)
Widowed	1 (1%)	1 (1%)	-
Separated	1 (1%)	1 (1%)	-
Total	95 (100%)	69 (73%)	26 (27%)

#### *Health of parents/carers*

24 (25%) participants reported suffering from chronic health problems, including 19 in N.I. and 5 in R.O.I.. Of these, 9 (10%) suffered from asthma, 7 (8%) had mental health problems, 6 (7%) had arthritis, 4 (5%) had cardiac related illness, 3 (3%) had visual impairments, 1 had epilepsy, 1 had physical illness, and 6 (7%) had other illness, such as Crohn's disease, tissue disorder, ulcers, and Ulcerative Colitis.



*Occupational status of parents/carers*

Table 2 shows the employment status of parents/carers. More than half of them were unemployed due to being full-time carers of the child with ASD. Part-time workers reported working an average of 18 hours per week and full-time employees worked an average of 36 hours per week.

**Table 2: Employment status of parents/carers.**

	<b>n</b>	<b>N.I.</b>	<b>R.O.I.</b>
Unemployed	45 (48%)	31 (45%)	14 (56%)
Employed Part Time	30 (32%)	24 (35%)	6 (24%)
Employed Full Time	17 (18%)	12 (17%)	5 (20%)
Student: 1 full-time; 1 part-time	2 (2%)	2 (3%)	-
Total*	94 (100%)	69 (73%)	25 (27%)

\* Data missing for one parent

*Occupational status of partners*

63 (77%) partners of the parents/carers who were married/cohabiting were employed full-time, 7 (9%) were employed part-time, and the remaining 11 (14%) were unemployed (Table 3).

**Table 3: Employment status of partners.**

	<b>n</b>	<b>N.I.</b>	<b>R.O.I.</b>
Partner unemployed	11 (14%)	7 (12%)	4 (16%)
Partner employed part-time	7 (9%)	4 (7%)	3 (12%)
Partner employed full-time	63 (77%)	45 (81%)	18 (72%)
Total	81 (100%)	56 (69%)	25 (31%)

Partners who were employed full-time worked an average of 44 hours per week, while partners who were employed part-time worked an average of 20 hours per week.

*Educational attainment*

In N.I. 58 (84%) parents stated their highest educational attainments were at General Certificate of Secondary Education (GCSE) level, or at Advanced Level General Education (A-level) (n=20), Irish Leaving Certificate (n=2), further and higher education such as National Diplomas, Higher National Diplomas, National Vocational Qualifications (NVQ) or City and Guilds qualification (n=12). 16 parents had studied to degree standard, 3 parents had attained a postgraduate qualification or Masters level education, and 5 parents had attained professional qualifications.

In R.O.I. 22 (85%) parents reported their highest educational attainments were Irish Leaving Certificate (n=9), further and higher education, such as National Diplomas (n=2), university degree standard (n=5), postgraduate qualification or Masters level (n=4), or professional qualifications (n=2).

*Family composition*

Apart from the target child, 81 (85%) families had an average of 2 other children (mean age of 10 years), 57 from N.I. and 24 from R.O.I..

In 23 (25%) of these families at least one of the other children had a formal diagnosis, 15 from N.I. and 8 from R.O.I.; the majority of these children were male (n=17; 74%) and had a mean age of 11 years.

11 (48%) of the siblings were diagnosed with ASD, 6 (55%) in N.I. and 5 (45%) in R.O.I.; 3 (27%) siblings were diagnosed with Asperger Syndrome (all N.I.), 2 (18%) with epilepsy, and one each with ADHD, Bardet syndrome, cancer, psychiatric illness, dyspraxia, and language impairment.

## Children

Parents reported on a total of 100 children. 72 of these children resided in N.I. and the remaining 28 resided in R.O.I.. Table 4 reflects a gender distribution of 4:1 (boys:girls).

**Table 4: Gender distribution of children.**

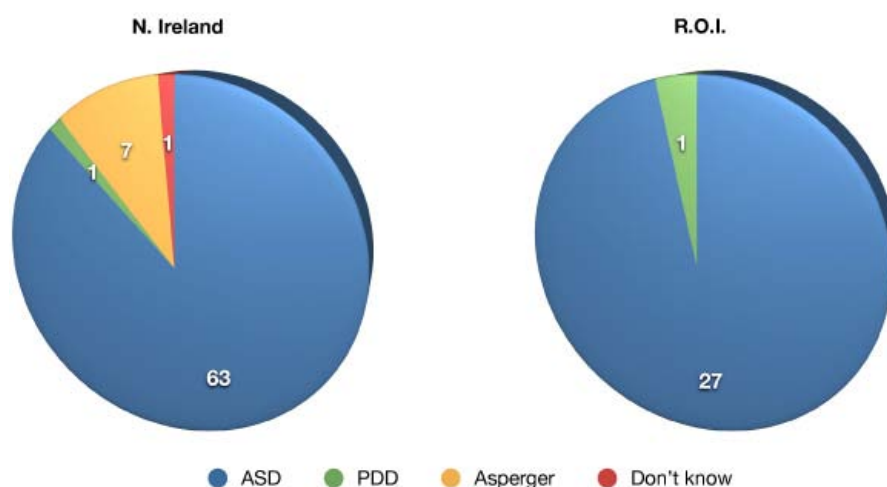
	n	N.I.	R.O.I.
Male	80 (80%)	56 (78%)	24 (86%)
Female	20 (20%)	16 (22%)	4 (14%)
Total	100 (100%)	72 (72%)	28 (28%)

The mean age of the children was 8 years, with 30 children aged between 1-6 years, 56 children aged between 7-12 years, 11 children aged 13-15 years, and 3 children aged over 16 years.

### Primary diagnosis

90 of the children had a formal diagnosis of Autism spectrum disorder (ASD), 7 of children were diagnosed with Asperger Syndrome, 2 of children were diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and the diagnosis of one child was unknown. Figure 4 reflects the distribution of diagnoses within the two demographic regions.

**Figure 4: Distribution of ASD**





*Dual diagnoses*

78 (78%) children had dual diagnoses, including 57 children from N.I. and 21 children from R.O.I.. Dual diagnoses meant that these children were diagnosed with ASD as well as intellectual disability, physical and sensory disability, or other concurrent diagnoses.

*Intellectual disability:* 56 (56%) children had diagnoses of ASD and learning disability (LD), including 40 children from N.I. and 16 children from R.O.I.. Severity of LD was recorded in three categories (mild, moderate, and severe) for 49 of these children; 46 of these children had moderate and severe LD (Table 5).

**Table 5: Severity of learning disability.**

	n	N.I.	R.O.I.
Mild	3 (6%)	2 (5%)	1 (9%)
Moderate	23 (47%)	15 (40%)	8 (73%)
Severe	23 (47%)	21 (55%)	2 (7%)
Total	49 (100%)	38 (78%)	11 (22%)

*Physical and sensory disability:* 27 (27%) children had diagnoses of ASD and physical and sensory disabilities (PSD), including 20 children from N.I. and 7 children from R.O.I.; 18 of these children were also diagnosed with intellectual disability. Details of PSD were obtained for 22 children (Table 6).

**Table 6: Physical and sensory disabilities.**

	n	N.I.	R.O.I.
Sensory	12 (55%)	9 (56%)	3 (50%)
Motor co-ordination delay	2 (9%)	2 (13%)	-
Dyspraxia	3 (14%)	2 (13%)	1 (7%)
Auditory	2 (9%)	1 (6%)	1 (7%)
Physical	2 (9%)	1 (6%)	1 (17%)
Poor muscular tone	1 (4%)	1 (6%)	-
Total	22 (100%)	16 (73%)	6 (27%)

*Other concurrent diagnoses:* 28 (28%) children were diagnosed with ASD and other concurrent diagnoses, including 25 children from N.I. and 3 children from R.O.I. (Table 7). The most frequent concurrent diagnosis was Attention Deficit Hyperactivity Disorder (ADHD).

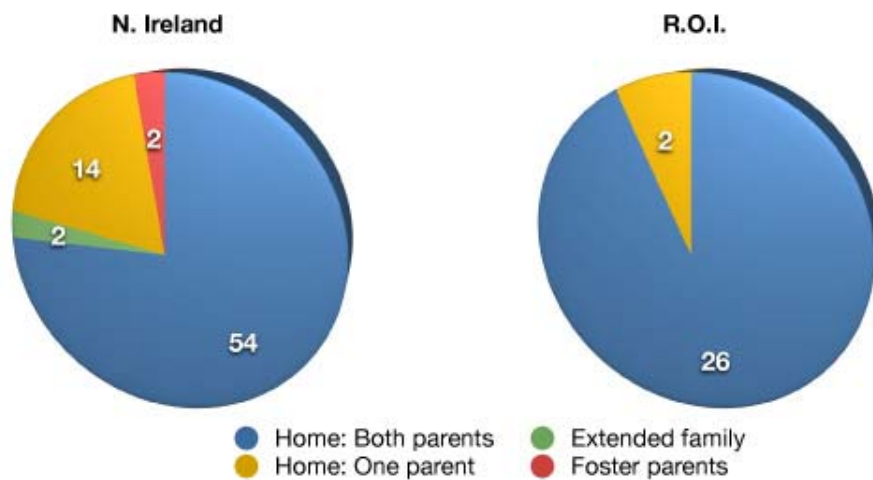
**Table 7: Other concurrent diagnoses.**

	n	N.I.	R.O.I.
ADHD	12 (42%)	12 (48%)	-
ADHD and epilepsy	2 (7%)	1 (4%)	1 (33%)
Asthma	2 (7%)	2 (8%)	-
Hyperactivity	1 (4%)	1 (4%)	-
Language delay	2 (7%)	2 (8%)	-
OCD* and depression	1 (4%)	1 (4%)	-
Epilepsy	6 (21%)	5 (20%)	1 (33%)
Developmental delay	1 (4%)	1 (4%)	-
Unknown	1 (4%)	-	1 (33%)
Total	28 (100%)	25 (89%)	3 (11%)

\*Obsessive Compulsive Disorder.

#### *Residential circumstances of children*

80 (80%) children lived at home with both parents, 16 children lived in one-parent families, 2 children resided with their extended family, and 2 children were in foster care. Figure 5 reflects residential circumstance within the two demographic regions.

**Figure 5: Residential circumstances of children.**


#### **Professionals**

67 professionals participated, 21 (31%) from N.I. and 46 (69%) from R.O.I.. 59 (88%) of the professionals were female and the remaining 8 (12%) were male.

With regard to educational attainment, 19 (29%) professionals had studied to degree level, 16 (23%) had obtained Masters level education, 10 (15%) had obtained PhD level education, 4 (6%) had acquired professionally recognised qualifications, 13 (20%) had obtained a Diploma, and 3 (4%) had obtained a Higher Diploma (H. Dip).

### Employment settings

In N.I., 19 (90%) professionals were employed by one of the Health and Social Services Trusts (HSST), 1 (5%) by the Department of Education N.I. (DENI), and 1 (5%) by a voluntary organisation (not specified).

In R.O.I., 22 (48%) professionals were employed by the Health Service Executive (HSE), 2 (4%) by the Department of Education and Science, 5 (11%) by voluntary organisations, and 17 (37%) by other organisations, such as voluntary sector schools, Universities, or independent bodies.

The mean duration of employment in their current post was 74 months (over 6 years); 122 months (10 years) in N.I. and 51 months (over 4 years) in R.O.I.. Data for one professional who had been in the same job for 384 months (32 years) was removed from the calculations to avoid skewing the data. Table 8 shows current jobs of participating professionals.

**Table 8: Current jobs of professional participants.**

Current job	n*	Current job	n
Speech & language therapist	13 (20%)	Education director	1 (1%)
ABA tutor	11 (17%)	Teacher	1 (1%)
Social worker	10 (15%)	Health visitor	1 (1%)
Clinical psychologist	9 (14%)	LD co-ordinator	1 (1%)
Autism therapist	3 (4 %)	Paediatrician	1 (1%)
Occupational therapist	4 (6%)	Dietician	1 (1%)
Children ward manager	2 (3%)	Behaviour analyst	1 (1%)
Behaviour support worker	2 (3%)	Psychiatry	1 (1%)
Educational psychologist	2 (3%)	Liaison officer	1 (1%)
Learning disability nurse	2 (3%)		

\*Data missing (n=2).

The current employment settings of 31 (46%) professionals was autism specific; 16 (24%) were currently employed in generic services with an ASD focus; 13 (20%) were employed in intellectual disability and autism services, and 7 (10%) were employed in social work, mental health services, and hospitals. Table 9 reflects the current employment setting of participating professionals.

**Table 9: Current employment settings of professional participants.**

Current setting	n	Current setting	n
Multi-disciplinary team	37 (55%)	Mainstream education	11 (16%)
Assessment	28 (42%)	Special needs education	11 (16%)
Autism specific education	28 (42%)	Residential & respite	11 (16%)
Early intervention team	14 (21%)	Adult day services	4 (6%)
Family support services	9 (14%)		

The case load of 30 (45%) professionals was 100% ASD specific, for 10 (15%) professionals the caseload was 50%-75% ASD specific, for 12 (18%) the caseload was

25% ASD specific, and 11 (16%) professionals worked with ASD in 10% or less of their caseload; 4 professionals stated that the question was not applicable to them.

The case load of 51 (78%) professionals involved children under the age of 18 years while 14 (22%) professionals worked with individuals of all ages. The question was not applicable to two professionals who worked within academia.

## 10.2 Research instruments

Two questionnaires were specifically designed for the study. The first questionnaire, the Family Autism Needs Questionnaire (FAN-Q), was designed for parents/carers (Appendix 1). The second questionnaire, the Professional Autism Needs Questionnaire (PAN-Q), was designed for professionals (Appendix 2). The General Health Questionnaire (GHQ-12) was included as a validated measure of parental general psychological health and stress levels. Focus groups were conducted to obtain qualitative data.

### *Family Autism Needs Questionnaire (FAN-Q)*

The FAN-Q included questions regarding four main areas:

- *Child-related information:* age, gender, demographic information, diagnoses, Special Education Needs Statements (SENs), current residential circumstance, and family composition;
- *Parent-related information:* age, gender, demographic and employment situation;
- *Assessing current provision and future needs:*
  - Home tuition programme,
  - Day service provision, i.e., schooling,
  - Financial support,
  - Multi-disciplinary support,
  - Home and respite support,
  - Individual care plans.
- *Parental experiences and views.*

### *Professional Autism Needs Questionnaire (PAN-Q)*

The PAN-Q was similar to the FAN-Q but included specific questions in order to ascertain the views and personal experiences of professionals working with families and children with ASD. The PAN-Q included questions regarding four main areas:

- *Professional-related information:* age, gender, demographic, training, and employment situation;
- *Experience of working with families and children with ASD;*
- *Perceived impact of ASD upon families and siblings;*
- *Future service needs for families living with a child with ASD.*

### *General Health Questionnaire (GHQ-12).*

The General Health Questionnaire is widely used, nationally and internationally, as an indicator of mental health states (Goldberg & William, 1988). It is not a diagnostic tool, although it has been used to indicate post-traumatic stress (Ouimette et al., 2007). The GHQ has high levels of reliability ( $\alpha > 0.88$ ; Hankins, 2007) and highly significant validity (Tait et al., 2002). Cross-cultural evaluations for example, have shown significant negative convergence with global quality of life scores ( $r = -0.56$ ,  $P < 0.0001$ ; Montazeri, 2003) and sensitivity and specificity scores of 80.6% and 79.3% respectively (Lee et al., 2005).

The GHQ has been developed in a variety of lengths using 12, 28, 30, and 60 questions. The 12-question version was used in this study because it is very quick to administer, has psychometric properties that are comparable to longer versions (Goldberg & William, 1988), and has been used extensively in N.I. (Murphy, & Lloyd, 2007).

There are a number of different scoring methods, including GHQ scoring (0-0-1-1); Likert scoring (0-1-2-3); modified Likert scoring (0-0-1-2); and C-GHQ scoring (0-0-1-1). As recommended by the test author, the GHQ scoring method (0-0-1-1) was used in this study (Goldberg et al., 1997). A threshold of 4 was used to indicate 'caseness', i.e., need for further psychological assessment (Goldberg & William, 1988).

#### *Focus group*

Semi-structured focus group discussions were conducted to collect qualitative data. Questions for discussion reflected the issues addressed in the FAN-Q.

### **10.3 Procedure**

The study was conducted between October 2006 and October 2007. Data collection took place from December 2006-September 2007.

#### *Literature review*

The literature search was conducted via a number of literature search engines (EBSCO host, Ovid online, and Science Direct), consultation of relevant peer-reviewed journals and books, conference attendance at Annual Convention of the Association of Behavior Analysis (San Diego, USA, May 2007) and RED Door Conference (Dublin, 2006), and discussions with parents and professionals.

#### *Pilot study*

For the pilot study, the FAN-Q was applied to 25 post-graduate psychology students and 4 parents. The PAN-Q was applied to 5 professionals. Feedback regarding the overall presentation, structure, clarity of questioning, and user friendliness of both questionnaires was received verbally and in writing. On the basis of this feedback, minor amendments were made to the FAN-Q, i.e., some services and financial entitlements were added. There were no amendments to the PAN-Q.

#### *Participant recruitment*

In the absence of a central database of children diagnosed with ASD, a research flyer was designed inviting parents of children with ASD to participate in the study (Appendix 3). The research flyer was circulated among all leading ASD charities in N.I., the Irish Autism Action (IAA), special schools and day services in both jurisdictions. The research flyer was also included in the quarterly bulletins of PEAT and IAA, and on the PEAT website ([www.peatni.org](http://www.peatni.org)). A presentation of the research flyer was given at PEAT and IAA meetings. Parents who decided to take part in the study contacted their child's school principal or the research team directly.

#### *Data collection*

FAN-Qs were distributed to parents either by surface mail (including stamped addressed return envelopes), e-mail, or in person at meetings or home visits. Questionnaires were completed and returned by surface mail, e-mail, or in person. Where requested, researchers helped with questionnaire completion. In total 310 questionnaires (FAN-Q) were

distributed to parents (return rate 31%), 160 in N.I. (return rate 43%) and 150 in R.O.I. (return rate 17%).

PAN-Qs as well as a letter inviting participation and asking for wide distribution were e-mailed to Department of Education N.I. (DENI), the Department of Health and Social Services (N.I.), regional offices of the Department of Education and Science (R.O.I.), and the Health Service Executive (R.O.I.). Where membership directories were publicly available, PAN-Qs were circulated by e-mail directly to members, e.g., British Psychological Society N.I. Branch (BPS) and the Psychological Society of Ireland (PSI). Due to lack of control over level of circulation, it is impossible to assess the exact number of PAN-Qs that were distributed. 67 completed questionnaires were returned via e-mail or surface mail.

A focus group was conducted with 10 parents from N.I. to collect qualitative data. Data collection took place in a quiet room in a local hotel and lasted one and a half hours. The discussion was tape-recorded and transcribed. Issues that were discussed were similar to those addressed in the FAN-Q.

#### **10.4 Statistical Analysis**

Using SPSS version 13 two data sets were created. The first data set was child specific and included data for 100 children. In order to avoid duplication of cases where questionnaires had been completed for more than one child ( $n=5$ ), this data set was manipulated (select cases) for all analyses that were parent focused. The second dataset was designed specifically for data regarding professionals. Cross tabulations were conducted to allow for conclusions to be examined on the basis of all collated responses in each dataset. In respect of parental General Health Questionnaire (GHQ-12) scores, independent samples t-test and Pearson correlation analysis were undertaken.

#### **10.5 Ethical considerations**

The School of Psychology Research Ethics Committee (University of Ulster) granted ethical approval for the study.

Participant information sheets and consent forms (Appendix 4) were given to each participant outlining the rationale for the study and assuring participants that information would be confidential and that their decision regarding participation (nor not) would not affect service provisions or entitlements (parents) or occupational status or relationships within that employment (professionals). Participants were also informed that they could withdraw from the study at any time without adverse consequences.

All hard copies of completed questionnaires were kept strictly secured in a safe environment as required under data protection.

## 11. Results

### 11.1 Diagnostic process.

The mean age at diagnosis was just over 4 years. Children in N.I. were slightly older when they received a diagnosis than were children living in R.O.I. (Table 10).

**Table 10: Age at diagnosis (years).**

	n*	Minimum	Maximum	Mean	SD**
N.I.	68	2.0	13.0	4.5	2.28
R.O.I.	28	1.7	8.0	3.2	1.35
Total Sample*	96	1.7	13.0	4.1	2.13

\*Data missing (n=2); data excluded (n=2) due to much older age at diagnosis (16 and 22 years).

\*\*Standard deviation.

Between first referral and diagnosis an average of 16 months elapsed in N.I.; an average of 14 months elapsed in R.O.I. (Table 11). In 53 (57%) cases diagnosis was completed in less than 12 months, in 12 (13%) cases the process took over 12 months, and in 28 (30%) cases the process took more than 24 months.

**Table 11: Duration of diagnosis (months).**

	n*	Minimum	Maximum	Mean	SD**
N.I.	61	1	54	16	12.46
R.O.I.	26	1	60	14	11.98
Total Sample*	87	1	60	16	12.28

\*Data missing (n=7); data excluded (n=2) due to much longer duration (96 and 108 months); data excluded (n=4) due to private diagnosis (average duration 2.5 months).

\*\*Standard deviation.

Parental experiences varied across the diagnostic process. The majority of the parents who received a diagnosis through statutory Health and Social Services did not think that the process was completed in a timely and professional manner (Table 12) or that information was presented clearly (Table 13).

**Table 12: Duration of and professional conduct during diagnosis.**

Diagnosis was completed in a timely and professional manner	N.I. n	R.O.I. n	Total n
Agree completely	7 (11%)	2 (7%)	9 (10%)
Agree	21 (31%)	5 (19%)	26 (28%)
Neutral	7 (11%)	2 (7%)	9 (10%)
Disagree	17 (26%)	8 (30%)	25 (27%)
Completely disagree	14 (21%)	10 (37%)	24 (25%)
Total*	66 (66%)	27 (27%)	93 (100%)

\*Data missing (n=3); data excluded (n=4) due to private diagnosis.

One of the parents said during the focus group

*“Waiting time for referral: Knew from 18months that something was wrong, but health visitor put me off, said I was labelling my child”.*

**Table 13: Presentation of diagnostic information.**

<b>Information clearly presented and easily understood</b>	<b>N.I. n</b>	<b>R.O.I. n</b>	<b>Total n</b>
Agree completely	4 (6%)	3 (11%)	7 (7%)
Agree	21 (31%)	4 (15%)	25 (27%)
Neutral	10 (15%)	3 (11%)	13 (14%)
Disagree	14 (21%)	11 (41%)	25 (27%)
Completely disagree	18 (27%)	6 (22%)	24 (25%)
Total*	67 (67%)	27 (27%)	94 (100%)

\*Data missing (n=2); data excluded (n=4) due to private diagnosis.

Most parents felt that support and advice from statutory providers was not sufficient for their child and family (Table 14), in particular with regard to financial entitlements (Table 15).

**Table 14: Support and advice from statutory providers.**

<b>Support and advice regarding services was sufficient</b>	<b>N.I. n</b>	<b>R.O.I. n</b>	<b>Total n</b>
Agree completely	1 (1%)	1 (4%)	2 (2%)
Agree	11 (16%)	-	11 (11%)
Neutral	5 (7%)	3 (11%)	8 (8%)
Disagree	25 (36%)	9 (32%)	34 (35%)
Completely disagree	28 (40%)	15 (53%)	43 (44%)
Total*	70 (70%)	28 (28%)	98 (100%)

\*Data missing (n=2).

**Table 15: Information and advice regarding financial entitlements.**

<b>Advice regarding the financial entitlements was sufficient</b>	<b>N.I. n</b>	<b>R.O.I. n</b>	<b>Total n</b>
Agree completely	1 (1%)	1 (3.5%)	2 (2%)
Agree	16 (23%)	1 (3.5%)	17 (18%)
Neutral	6 (9%)	2 (7%)	8 (8%)
Disagree	15 (22%)	12 (43%)	27 (28%)
Completely disagree	31 (45%)	12 (43%)	43 (44%)
Total*	69 (69%)	28 (28%)	97 (100%)

\*Data missing (n=3).

In the focus groups, parents expressed their views about the diagnostic process as follows:

*“Took 11 years, not long enough to talk about my son.”*

*“Did the process in 1.5 hours, asked a few questions, like does the child (aged 2.5yrs) like curry? The answer was no. Then the professional said the child has Autism.”*

*“No proper assessment in place.”*



*“No information on what to do next.”*

*“Terrible ADHD until he was 16 years of age. Then the teacher in a special school woke up. The teachers should know want to look out for and inform the parent.”*

*“Consultant gave written diagnoses of ADHD/Dyspraxia. Then rang me at work to say she forgot to put down Aspergers, but sure I knew anyway. I didn’t and was left devastated at work.”*

*“Cohesive services offered immediately after diagnoses”*

The majority of the professionals (n=58; 87%) agreed that parents were likely to experience significant distress when trying to access the diagnostic process, however, only half of the professionals reported that they had noticed parental distress (Table 16).

**Table16: Professional view of parental distress.**

Parents were distressed	N.I. n	R.O.I. n	Total n
Noticed	16 (76%)	16 (35%)	32 (48%)
Not noticed	5 (24%)	30 (65%)	35 (52%)
Total	21 (31%)	46 (69%)	67 (100%)

**Key points:** Diagnostic process

- The diagnostic process took on average 16 months to complete.
- 53% of the parents/carers either disagreed or completely disagreed that their child’s diagnosis was completed in a timely and professional manner.
- 52% of the parents/carers either disagreed or completely disagreed that the information they received following their child’s diagnoses was clearly presented and easily understood.
- 79% of the parents/carers disagreed or completely disagreed that they received sufficient support and advice regarding services for their child and family.
- 72% of the parents/carers disagreed or completely disagreed that their child’s diagnosis, they received sufficient information and advice regarding the financial entitlements available to their child and family.
- 87% of the professionals agreed that parents/carers experience significant distress trying to access a formal diagnosis for their child with ASD.

## 11.2 Special Education Needs Statement (SENS)

In N.I., 58 (80%) children had a Special Education Needs Statement (SENS); 10 (14%) children were awaiting a SENS to be issued; and 4 children did not have a SENS. The children were on average 5 years old when they received the SENS and it took an average of 10 months to be issued (Table 17).

**Table 17: Time taken to issue SENS in N.I. (months).**

	n*	Min.	Max	Mean	SD
SENS	54	1	36	10	6.10

\*Data missing (n=4).

The 10 children still waiting to be issued a SENS had already waited 6 months (n=6), 24 months (n=1), and 48 months (n=1). Data were missing for 2 of the waiting children. For those who had received SENS (n=58), parents were of differing opinion with regard to accuracy and appropriateness of SENS (Table 18).

**Table 18: Parent/carer views regarding SENS.**

	Yes n	No n
Child's SENS accurately describes individual needs	33 (56%)	25 (44%)
Provisions outlined in SENS are appropriate to child's needs	29 (50%)	29 (50%)

In the focus groups, parents expressed their views about the 'statementing' process as follows:

*"It was not a true overall result, professionals gave the impression they knew all the right questions to ask. But they never asked me what I knew about my child, considering mother always knows best."*

*"Sporadic, no provisions and no support, inappropriate terminology, e.g., autistic tendencies."*

*"Lots of red tape and policies – waste of time. Up to one year spent on choice of school."*

*"While I was glad to get a SENS, it was never taken seriously. Most parents don't know enough regarding their rights."*

*"Statement too generalised, statement includes the provision of occupational therapy, but I had to wait two years. After I received support form ... received occupational therapy within two weeks."*

*"Extremely hard to understand and complete, I think that you should be able to get the help needed."*

*"Once we received our statement, we did get help in primary school, however when my child is not coping in placements, we had to wait until all MDT involved in statement chipped in, and this took too long."*

#### **Key points: SENS process**

- The process of being issued a SENS took on average 10 months to complete.
- 44% of the parents/carers felt their child's SENS did not accurately describe their child's individual needs.
- 50% of the parents/carers felt the provisions outlined in their child's statement

- were not appropriate to their child's needs.
- The process of being issued a formal diagnosis and being issued a SENS in N.I. took on average 26 months to complete.

### 11.3 Home tuition programmes

#### *Programme approach*

Just over half of the participating children (n=53) were receiving ASD specific home tuition. The majority of home tuition programmes were conducted in N.I. and were based on ABA (Table 19). Of the 24 children from R.O.I. attending ABA schooling only 4 (17%) received ABA home tuition programmes as well.

**Table 19: Home tuition programme approach.**

	N.I. n	R.O.I. n	Total n
Applied Behaviour Analysis (ABA)	42 (89%)	6 (100%)	48 (91%)
ABA & TEACCH	4 (9%)	-	4 (8%)
TEACCH	1 (2%)	-	1 (1%)
Total	47 (65%)	6 (21%)	53 (100%)

In N.I. the average age at which children commenced ABA home tuition programmes was 6 years (n=39) while in R.O.I. the average age was 3 years of age (n=5). The average length of ABA home tuition programmes was 22 months in N.I. and 27 months in R.O.I.. The 4 children who receiving ABA and TEACCH home programmes had an average age of 4 years and had been in the programme for an average of 15 months.

The majority of the parents had learned about ABA home tuition programmes through personal research (n=15; 33%), from other parents of children with ASD (n=14; 30%), or from friends and family, charities, school seminars (n=11; 24%). Few had heard about ABA home tuition programmes from statutory bodies or professionals (n=6; 13%).

#### *Programme delivery*

The majority of the parents delivered ABA home tuition programmes with the support of a trained behaviour analyst (BCBA/PhD level) or an ABA home tutor (n=25; 52%); only 2 parents were supported by school staff, extended family, or friends. Some parents who carried out the programme by themselves used support from a behaviour analyst or a home tutor as a secondary mode of delivery, i.e., not as the main way of delivering the programme but as occasional support (n=14; 29%) (Table 20).

Of the 25 ABA programmes that were supervised by a behaviour analyst, 1 involved 8 hours input by the behaviour analyst per week and the remaining 24 programmes involved 2 hours supervision per month provided by the behaviour analyst.

Most non-intensive ABA home programmes (n=28) lasted less than 10-20 hours per week and were carried out by parents alone or with a home tutor, while some of the more intensive programmes (n=15) were conducted by both parents on a 24/7 basis (Table 21).

**Table 20: Mode of delivery of ABA home tuition programmes.**

Primary mode of programme delivery	n	Secondary mode of delivery			
		BA**	Tutor***	School	Family
Parent & BA**	14 (29%)	-	-	-	-
Parent alone	13 (27%)	4 (31%)	4 (31%)	-	-
Parent & tutor***	9 (19%)	3 (33%)	-	-	-
Both parents	7 (15%)	3 (43%)	-	-	-
Behaviour analyst** only	2 (4%)	-	-	-	-
In partnership with school	1 (2%)	-	-	-	-
Parent & extended family	1 (2%)	-	-	-	-
Total*	47 (100%)	10 (20%)	4 (8%)	-	-

\*Data missing (n=1)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

\*\*\* Not formally qualified home tutor, usually with some basic training in ABA.

**Table 21: Duration of ABA home tuition programmes.**

Delivery method	n	Hours per week			
		1-9	10-19	20-29	30+
Parent & BA**	13 (31%)	8 (57%)	3 (21%)	-	2 (14%)
Parent alone	12 (28%)	6 (50%)	4 (34%)	-	2 (16%)
Both parents	6 (14%)	-	-	-	6 (100%)
Parent & tutor***	9 (21%)	2 (22%)	3 (34%)	2 (22%)	2 (22%)
BA** only	1 (2%)	-	-	-	1 (100%)
With school	1 (2%)	-	1 (100%)	-	-
Parent & ext. family	1 (2%)	-	1 (100%)	-	-
Total*	43 (100%)	16 (37%)	12 (28%)	2 (5%)	13 (30%)

\*Data missing (n=5)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

\*\*\* Not formally qualified home tutor, usually with some basic training in ABA.

Parents conducted 3 of the 4 combined ABA and TEACCH home tuition programmes alone, although a behaviour analyst or school TEACCH programme supported 2 of these programmes through the secondary mode of delivery; the remaining programmes were conducted by both parents. One of these programmes was non-intensive (1-9 hours per week); one was conducted 10-19 hours per week; and one was a high-intensity programme (30+ hours per week).

In the focus groups, parents expressed their experiences of delivering ABA home tuition programmes as follows:

*“Child has become much more social, a real transition, ABA has had a wonderful impact on our lives – child is responding really well with the different strategies they put in place. Feel child’s school should embrace ABA and apply it where it is needed / required.”*

*“Impact of ABA has been great, since PEAT came monthly to visit. Lifeline to help me with problems. Puts things in perspective, I feel less helpless as I keep trying to overcome problems.”*

*“ABA has made a huge change to our family life. We can now understand that our child is not just being badly behaved, we can make changes to a child’s life to enable her to lead a more functional life.”*

*“ABA has saved my life.”*

*“ABA is our way of life, very positive. Have become very knowledgeable able to understand children’s behaviour, feel more confident to be a good mother to my family.”*

#### *Programme monitoring*

The vast majority of the ABA home programmes had one or more monitoring procedures in place, while only 3 programmes (1 in N.I. and 2 in R.O.I.) did not have any monitoring procures in place (Table 22).

**Table 22: Home programme monitoring systems.**

Monitoring method	n
Graphs/observational charts	39 (89%)
Tables	19 (43%)
Notes/commentaries	33 (75%)
Behaviour analyst** supervision	39 (89%)
Total	44 (100%)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

All 4 ABA and TEACCH home programmes had monitoring procedures in place; 2 used graphs and observation charts; 2 used tables; and 2 used notes/commentaries. All were supervised and monitored by a behaviour analyst.

#### *Cost of home tuition programmes*

There were substantial variations (£250 - €20,000) in annual cost of ABA home tuition programmes (Table 23). Two outlying data points (£20,000 and £22,000) were excluded to avoid skewing of data.

**Table 23: Annual cost of ABA home tuition programme.**

	n	Minimum	Maximum	Mean	SD*
N.I.	20	£250	£10,000	£3,442	3.28
R.O.I.	3	€ 7,000	€ 20,000	€ 13,333	6.51

\*Standard deviation.

Only 2 participants received financial support for annual cost of ABA and TEACCH home programmes (£80 and £500).

#### *Social validity*

Based upon 45 responses from parents delivering ABA home tuition programmes, 40 (89%) felt that ABA programmes were always specific and appropriate to their child’s needs, 4 (9%) felt the ABA programme was sometimes appropriate to their child’s needs, and 1 (2%) was unsure.

Of the parents who delivered ABA and TEACCH home tuition programmes, 2 felt the programmes were always appropriate to their child's need and 2 parents felt their programmes were sometimes appropriate to their children's needs.

#### *Future requirements*

Of the 53 children in receipt of a home tuition programme, 44 (83%) require a home tuition programme in the future (39 in N.I. and 5 in R.O.I.); while 6 (11%) parents were undecided about requirements; and 2 (4%) children did not require a home tuition programme in the future (data missing n=1).

All of the parents who were undecided about future needs or who stated that they did not require a home tuition programme were implementing an ABA programme at present and 5 of these parents considered their child's programme as always appropriate to their child's needs.

The parent presently implementing a TEACCH programme only was undecided whether to implement a home tuition programme in the future and was unsure whether the programme was appropriate to the child's needs.

The parent implementing an ABA and TEACCH home programme considered the programmes appropriate to the child's needs and was undecided as to whether a home tuition programme was required in the future.

Of the 41 children presently not in receipt of a home tuition programme, 19 (46%) did not require a home tuition programme in the future, 12 (29%) parents were undecided as to whether or not to implement a programme, and 3 (7%) required a home tuition programme in the future (data missing n=7).

Of the 6 children for whom data were missing in respect of current home tuition, 3 did not require a home tuition programme in the future and 1 required a TEACCH programme (missing data n=2).

In total, over half of the parents reported that their children required home tuition programmes in the future; 97%-100% of these programmes should be ABA home tuition programmes (Table 24).

**Table 24: Future requirements for home tuition programmes.**

Requirement	N.I. n	R.O.I. n	Total n*
Home tuition required	42 (59%)	6 (32%)	48 (54%)
Home tuition not required	13 (18%)	10 (53%)	23 (25%)
Undecided	16 (23%)	3 (15%)	19 (21%)
Total*	71 (79%)	19 (21%)	90 (100%)

\*Data missing (n=10).

41 (85%) parents required ABA home tuition for their children in the future, 35 from N.I. and 6 from R.O.I.. 6 (13%) N.I. parents stated that they required ABA and TEACCH home tuition for their children and 1 (3%) N.I. parent required TEACCH for their child.

While for nearly half the children (n=22) an average of 17+ hours per week ABA home tuition programmes will be required in the future, some children (n=8; 20%) will require up to 25-40 hours (Table 25).

**Table 25: Duration of ABA home tuition programmes (hours).**

	n	Min	Max	Mean: Hours	SD*
Hours per week	22	6.0	40.0	17.3	9.91

\*Standard deviation.

#### *Future programme delivery*

Most parents require future ABA home tuition for their children delivered in collaboration with a trained and qualified behaviour analysts or home tutors (n=27; 65%) and would welcome support from their children's schools (Table 26).

**Table 26: Future need for delivery of ABA home tuition programmes.**

Primary mode of programme delivery		Secondary mode of delivery			
	n	BA**	Tutor***	School	Family
Parent & BA**	21 (51%)	-	2 (9%)	9 (43%)	4 (19%)
Parent alone	1 (2%)	1 (100%)	-	-	-
Parent & tutor***	6 (15%)	1 (17%)	-	2 (33%)	-
Both parents	2 (2%)	-	-	-	-
BA** only	3 (7%)	-	-	-	-
With school	8 (19%)	4 (50%)	1 (13%)	-	-
Parent & family	-	-	-	-	-
Total*	41 (100%)	6 (15%)	3 (7%)	11 (27%)	4 (10%)

\*Data missing (n=7).

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

\*\*\* Not formally qualified home tutor, usually with some basic training in ABA.

Parents who presently run ABA and TEACCH programmes (n=6) stated that they require supervision by a qualified behaviour analyst (n=4), and/or support from school (n=2), tutor (n=2), or extended family (n=1).

Table 27 compares current provision and future needs for all home tuition programmes. The overall need for future provision of primary and secondary mode services from qualified behaviour analysts (with parents and BA alone) (n=46) outweighs the present provision (n=16) by nearly 3:1. The future need of services from ABA home tutors (n=10) remains similar to present provision (n=11). The future need of school support (n=14) rises from present provision (n=1) at a ratio of 14:1. The needs of the parents working alone with their child reduced from 26 to 2 (ratio 13:1) and the need of both parents working with the child reduced from 12 to 2 (ratio 6:1).



**Table 27: Comparison between current and future mode of programme delivery.**

Current primary mode of delivery	n	Secondary mode	Future primary mode of delivery	n	Secondary mode
Parent & BA**	14 (27%)	-	Parent & BA**	25 (53%)	18 (72%)
Parent alone	16 (31%)	10 (63%)	Parent alone	1 (2%)	1 (100%)
Parent & tutor***	9 (17%)	3 (33%)	Parent & tutor***	7 (15%)	3 (43%)
Both parents	8 (15%)	3 (38%)	Both parents	2 (4%)	-
BA** only	2 (4%)	-	BA** only	3 (7%)	-
With school	1 (2%)	-	With school	9 (19%)	5 (56%)
Parent & family	1 (2%)	-	Parent & family	-	-
Total*	52 (100%)	16 (31%)	Total*	47 (100%)	27 (57%)

\*Data missing (n=1).

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

\*\*\* Not formally qualified home tutor, usually with some basic training in ABA.

In the focus groups, parents talked about professional responses to parental delivery of an ABA programme:

*“Got the impression they thought I was on a fool’s errand.”*

*“Professionals feel pity towards parents doing ABA.”*

*“Not seen as a service or therapy.”*

#### 11.4 Parent training

60 (63%) parents had received training in ASD, ABA and/or other; 51 from N.I. and 9 from R.O.I.. Table 28 shows that most parents had received more than one mode of training and that ABA training (117 responses) was more frequently used than other training modes (57 responses), at a ratio of approximately 2:1.

**Table 28: Parent training modes.**

ABA training mode	n
ABA Workshop, conference	38 (63%)
ABA 1:1 Supervision by a behaviour analyst**	37 (61%)
ABA Short Courses	24 (40%)
ASD 1:1 Supervision by a behaviour analyst**	18 (30%)
<b>Other training modes</b>	
ASD Workshop, conference	30 (50%)
ASD Short courses	20 (33%)
Other	7 (12%)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

29 of these parents had received an average of 23 hours ASD specific training; 37 parents had received an average of 24 hours ABA specific training (excluding one parent who had received 200 hours ABA specific training); and 7 parents had received 24 hours of training in a variety of other approaches.



23 partners of primary carers had received training in ASD, ABA, and/or other; 16 from N.I. and 7 from R.O.I.. Table 29 shows that most partners had received more than one mode of training and that ABA training (38 responses) was more frequently used than other training modes (22 responses), at a ratio of nearly 3:2.

**Table 29: Partner training modes.**

<b>ABA training mode</b>	<b>n</b>
ABA Workshop, conference	11 (69%)
ABA Short courses	10 (62%)
ABA 1:1 Supervision by a behaviour analyst**	9 (56%)
ASD 1:1 Supervision by a behaviour analyst**	8 (50%)
<b>Other training modes</b>	
ASD Workshop, conference	10 (62%)
ASD Short courses	10 (62%)
Other	2 (13%)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

6 of the partners had received an average of 68 hours ASD training (excluding one partner who had received 1000 hours of ASD training). 6 partners had received an average of 32 hours of ABA training (excluding one partner who had received 500 hours of ABA training). 2 partners had received 155 hours of training in variety of other approaches.

In the focus groups, parents expressed how professionals reacted to ABA home tuition programmes:

*“They don’t want to know, I think that as long as you want to do it yourself and you don’t want any assistance from them they are happy to let you do it.”*

*“No reaction, thought maybe I’d just imagine myself talking.”*

*“Extremely awful, feel I am on trial when they visit the home as if I am an ABA Nazi.”*

#### *Treatment integrity*

As stated earlier, 52 (52%) children were in home tuition programmes. 48 of these children were in ABA programmes and 4 children were in combined ABA and TEACCH programmes. 47 (50%) parents were personally involved in home programmes; 42 from N.I. and 5 from R.O.I..

Treatment integrity was monitored through competency-based assessment for 35 (74%) of these parents, all them were from N.I.; in addition one parent completed a multiple-choice test and one parent was observed during programme delivery.

#### *Future parent training needs*

39 (98%) of the parents who require future home programmes for their child had future training needs, 36 (92%) from N.I. and 3 (8%) from R.O.I..

Table 30 compares current training modes with future training needs and shows that most parents require future training in more than one mode and that ABA training (169 responses) was more frequently required than other training modes (92 responses).

**Table 30: Comparison between current and future parent training requirements.**

Current ABA training	n	Future ABA training need	n
ABA Workshop, conference	49 (59%)	ABA Workshop, conference	42 (64%)
ABA 1:1 Supervision BA**	47 (56%)	ABA 1:1 Supervision BA**	47 (72%)
ABA Short courses	34 (41%)	ABA Short Courses	40 (61%)
ASD 1:1 Supervision BA**	26 (31%)	ASD 1:1 Supervision BA**	40 (61%)
<b>Other current training</b>		<b>Other future training need</b>	
ASD Workshop, conference	40 (48%)	ASD Workshop, conference	37 (57%)
ASD Short courses	30 (36%)	ASD Short courses	39 (60%)
Other	16 (19%)	Other	16 (25%)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

In the focus groups, parents discussed professional reactions to positive outcomes from ABA programmes:

*“No reaction, they would just ignore you when you call it an ABA programme – you are on your own.”*

*“As ABA is not seen as a viable therapy with the educational boards and our health boards, I know my understanding is greater than their’s.”*

*“I’ve discovered not to rely on professionals knowing what’s best for my child. In many areas, ABA being one of them, my knowledge by far outweighs theirs.”*

*“We as parents have a better understanding of ABA than most professionals.”*

**Key points: Home tuition**

- 53% of children received home tuition programmes, mainly in N.I.
- Only 13% of the parents heard about home tuition programmes from statutory professionals.
- The average cost associated with ABA specific programme in N.I. was £3,442 per annum. In the R.O.I, the average cost associated with an ABA programme was €13,333 (£9,270) per annum (ratio of nearly 1:3).
- 89% of the parents felt their ABA programme was always specific to their child’s needs.
- 98% of all future home tuition programmes require ABA.
- 52% of home tuition programmes currently in place include a behaviour analyst.
- In the future, all home programmes required a behaviour analyst.
- 4% of programmes currently are delivered in partnership with the child’s school.
- In the future, 45% of home programmes require partnership with school (primary and/or secondary mode of delivery).
- ABA training is the highest mode of training required by parents and partners

in the future. 72% of the parents require 1: 1 supervision by a qualified behaviour analyst in the future, 64% of the parents require ABA workshops or conferences, and 61% of the parents requiring ABA short courses.

### 11.5 Professional involvement and training in home tuition

30 (45%) professionals had been involved in home tuition programmes, 4 from N.I. and 26 from R.O.I. (Table 31). In N.I., 1 professional was involved in ABA programmes, one was involved in an ABA and TEACCH programme, and the other 2 were involved with other voluntary group programmes. In R.O.I., 16 were involved in ABA programmes, 1 in ABA and TEACCH, 2 in TEACCH programmes, and the remaining 7 were involved in other programmes.

**Table 31: Professional involvement in home programmes.**

Professional involvement	n
Applied Behaviour Analysis (ABA)	17 (58%)
ABA & TEACCH	2 (7%)
TEACCH	3 (10%)
Other	8 (25%)
Total	30 (100%)

20 professionals stated that they have been involved in home tuition programmes for an average of 23 months; and 14 stated that the average age at which a child commenced these programmes was 5 years.

13 (30%) professionals who worked in statutory services had been involved in home tuition programmes, 3 from N.I. and 10 from R.O.I., including 2 who had been involved in ABA programmes (in R.O.I.) and one who was involved in an ABA and TEACCH programme (in N.I.).

In the focus groups, parents expressed their experiences of seeking support from professionals to deliver ABA programmes:

*“School informed me that I should carry on with ABA programme at home, but they were not interested in bringing it into the school.”*

*“There is no support available.”*

*“They don’t know enough about it and believe it’s only suitable for children with more severe autism not Asperger Syndrome. Not True.”*

*“Asked for help from teacher, she looked at me as if I had horns.”*

*“They are not suitably trained; education promotes the combined skills approach.”*

#### *Professional training*

30 (40%) professionals reported that they had received ASD related training, 5 from N.I. and 25 from R.O.I., for an average of 43 hours (based on 13 responses). 25 (37%) professionals stated that they had studied ABA as part of their undergraduate or

postgraduate education, 8 from N.I. and 17 from R.O.I., for an average of 117 hours (based on 11 responses). 19 had received TEACCH training for an average of 30 hours (based on 13 responses), and 7 had received other related training for an average of 39 hours (based on 5 responses) (Table 32).

**Table 32: Professional training.**

Training	Conference/Workshop n	Short courses n	ABA** n	Total n=89
ASD	16 (70%)	8 (35%)	11 (48%)	26 (29%)
ABA	8 (35%)	12 (52%)	15 (65%)	35 (39%)
TEACCH	9 (39%)	10 (43%)	-	19 (21%)
Other	6 (26%)	1 (4%)	-	7 (8%)

\*\*Supervision from qualified behaviour analyst – trained to BCBA/PhD level.

7 (23%) professionals currently involved in home programmes, 1 from N.I. and 6 from R.O.I., had not received any training in ASD or ABA. Of those who were not involved in home programmes, 7 professionals reported to have received training in either ASD or ABA.

18 (27%) professionals had received training in monitoring methods, 3 from N.I. and 15 from R.O.I.; 12 of these professionals had received training in single-case designs, 12 had used tables or figures, 9 had used notes or commentaries, and 1 had used unspecified research designs. 15 of these professionals were presently involved in home tuition programmes, 2 from N.I. and 13 from R.O.I.. The other 15 (50%) professionals currently involved in home tuition programmes had not received training in evaluation methods.

8 (38%) of the professionals who had received training in home tuition programmes felt that all of their training provided the necessary skills, 9 (43%) felt some of their training provided the necessary skills, 3 (14%) felt that none of their training provided the necessary skills, and 1 was unsure.

#### *Treatment integrity by professionals*

Treatment integrity and skills of 14 (47%) of the 30 professionals who were involved in home programmes was monitored and assessed using multiple methods, including written examination (n=9), multiple choice test (n=9), competency-based training (n=13), and viva (n=1); these numbers include only 2 of statutory staff. 11 professionals who were involved in home programmes were not monitored or assessed (data missing n=5).

**Table 33: Future training needs for professionals.**

	Conf. & w'shop n	Short courses n	PG/Masters level n	Total n
ABA**	14 (21%)	32 (48%)	15 (22%)	61 (91%)
ASD	12 (18%)	30 (45%)	11 (16%)	53 (79%)
TEACCH	7 (10%)	31 (46%)	8 (12%)	45 (67%)
Other	2 (3%)	15 (22%)	2 (3%)	19 (28%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

*Future training needs for professionals*

The vast majority of the professionals (n=61; 91%) stated that they required training in ABA, with nearly one quarter considering Masters level training most appropriate. In addition, over three quarters of the professionals also required ASD training (Table 33).

**Key Points:** Professionals and home tuition

- 45% of the professionals stated that they were personally involved in home tuition programmes.
- 37% of the professionals stated that they had studied ABA as part of their undergraduate or postgraduate education.
- 30% of professional employed by statutory services had been involved in home tuition programmes, 15% from N.I. and 42% from R.O.I..
- 5% of the professionals employed by statutory services had been involved in ABA home tuition programmes (all in R.O.I.).
- 1 professional employed by statutory services in N.I. was involved in home tuition programmes involving ABA and TEACCH programmes.
- 40% of the professionals had received specific ASD and/or ABA training, 24% from N.I. and 54% from R.O.I..
- 23% professionals involved in home tuition programmes (1 from N.I. and 6 from R.O.I.) had not received any training; 3 of these stated that they had been involved in ABA programmes.
- 50% of the professionals involved in home tuition programmes had not received training on monitoring methods to evaluate programmes.
- 47% of the professionals involved in home tuition programmes had skills assessment in some form.
- 91% of the professionals stated that they required ABA training.

## 11.6 Day service and education provisions

50 (53%) parents had become aware of educational provision for their child from non-statutory services, 27 from N.I. and 23 from R.O.I., including 31 parents who did personal research, 15 who learned from other parents of children with ASD, 3 who became aware of educational provisions via other avenues, and one who had talked to friends and family.

**Table 34: Current day services.**

	<b>N.I. n</b>	<b>R.O.I. n</b>	<b>Total n</b>
Primary/secondary school	65 (90%)	28 (100%)	93 (93%)
Home tuition only	3 (4%)	-	3 (3%)
Third level education	2 (3%)	-	2 (2%)
No day service	2 (3%)	-	2 (2%)
Total	72 (72%)	28 (28%)	100 (100%)

46 (49%) parents had considered moving house in order to avail of educational provision more appropriate to their child's needs, 32 from N.I. and 14 from R.O.I.. 8 (8%) parents actually had moved house in order to avail of more appropriate educational services for their child, 3 from N.I. and 5 from R.O.I. (Table 34).

55 (82%) professionals had noted that parents of children on the autism spectrum experienced significant distress or difficulties accessing appropriate education, 16 from N.I. and 39 from R.O.I.

In the focus groups, parents talked about their experiences of seeking support to deliver ABA programmes:

*“Asked health professionals and they said that was educational responsibility. So asked education and was told it was the responsibility of health.”*

Of 65 children who attended school in N.I., 38 attended special needs schools or classes, while nearly one third attended mainstream school or nursery (n=24); only 2 attended a pre-school ABA class (Table 35).

**Table 35: School provision in N.I..**

	Pre-school n	Primary n	Secondary n	Total n
Special needs school	5 (42%)	18 (42%)	5 (50%)	28 (43%)
Mainstream class	-	17 (40%)	5 (50%)	22 (34%)
Special needs class	2 (17%)	8 (18%)	-	10 (16%)
Nursery	3 (25%)	-	-	3 (5%)
ABA class	2 (16%)	-	-	2 (2%)
Total	12 (18%)	43 (66%)	10 (16%)	65 (100%)

The average time of *pre-school* attendance was 17 hours per week (SD=6.99); the average teacher:pupil ratio was 1:2; the average distance travelled to and from pre-school was 18 miles (SD=15.6), although one child had a daily return journey of 70 miles. Most of the parents felt that all pre-school education was appropriate to their child's needs (n=9; 75%), while 3 (25%) parents felt that some pre-school education was appropriate to their child's needs.

The average time of *primary school* attendance was 26 hours per week (SD=6.20); the average teacher:pupil ratio was 1:2; the average distance travelled to and from primary school was 10 miles (SD=12.0). Some of the parents felt that all primary school education was appropriate to their child's needs (n=15; 35%), while most of the parents felt that some primary school education was appropriate to their child's needs (n=23; 54%). 4 (9%) parents felt their child's primary education was never appropriate and 1 (2%) parent was unsure on the appropriateness of their child's education provision.

The average time of *secondary school* attendance was 29 hours per week (SD=5.57); the average teacher:pupil ratio was 1:4; the average distance travelled to and from primary school was 15 miles (SD=15.7). Half of the parents felt that all secondary school education was appropriate to their child's needs (n=5; 50%), while the half felt that some secondary school education was appropriate to their child's needs (n=5; 50%).

Collectively, 29 (45%) parents felt their child's education provision in school in N.I. was always appropriate and 31 (48%) parents felt their child's education was sometimes appropriate to their child's needs. 4 (6%) parents felt their child's education provisions was

never appropriate and 1 (1%) parent was unsure on the appropriateness of their child's education provision.

Of 28 children who attended school in R.O.I., the majority attended ABA schools (n=23), while few attended special needs schools or classes or mainstream classes (n=5) (Table 36).

**Table 36: School provision in R.O.I..**

	Pre-school n	Primary n	Secondary n	Total n
Special needs school	-	2 (100%)	-	2 (7%)
Mainstream class	-	2 (100%)	-	2 (7%)
Special needs class	-	1 (100%)	-	1 (4%)
Nursery	-	-	-	-
ABA class	-	-	-	-
ABA school**	6 (26%)	17 (74%)	-	23 (82%)
Total	6 (21%)	22 (79%)	-	28 (100%)

\*\*Run by qualified behaviour analyst – trained to BCBA/PhD level.

The average time of *pre-school* attendance was 19 hours per week (SD=9.32); the average teacher:pupil ratio was 1:1; the average distance travelled to and from pre-school was 14 miles (SD=15.0). Most of the parents felt that all pre-school education was appropriate to their child's needs (n=5), while one parent felt that some pre-school education was appropriate to their child's needs.

The average time of *primary school* attendance was 26 hours per week (SD=8.80); the average teacher:pupil ratio was 1:1; the average distance travelled to and from primary school was 24 miles (SD=15.6). Most of the parents felt that all primary school education was appropriate to their child's needs (n=13), while some of the parents felt that some primary school education was appropriate to their child's needs (n=7), one parent was unsure. None of the children in R.O.I. were in receipt of secondary education.

Collectively, 18 (67%) parents felt their child's education provision in R.O.I. was always appropriate and 8 (30%) parents felt their child's education was sometimes appropriate to their child's needs; no parents felt their child's education provisions was not appropriate, and one parent was unsure on the appropriateness of her child's education provision.

**Table 37: Education monitoring methods in N.I..**

	Pre-school n	Primary n	Secondary n	Total n
Staff notes, commentaries	9 (75%)	34 (79%)	7 (70%)	50 (76%)
Graphs, observation charts	1 (8%)	7 (16%)	1 (10%)	9 (14%)
Tables	1 (8%)	5 (12%)	1 (10%)	7 (11%)
BA** supervision	3 (25%)	3 (7%)	1 (10%)	7 (11%)
Other	-	2 (5%)	-	2 (3%)
Total	14 (83%)	51 (81%)	10 (70%)	75 (100%)

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.



*Monitoring educational provision*

In N.I., educational provision was monitored in 52 (80%) cases, including 10 pre-schools, 35 primary schools, and 7 secondary schools, using a range of monitoring methods (Table 37). The main monitoring method was staff notes and commentaries.

In R.O.I., educational provision was monitored in 23 (82%) cases, including 6 pre-schools and 17 primary schools, using a range of monitoring methods (Table 38). The main monitoring method was supervision by a BCBA/PhD level qualified behaviour analyst and/or using graphs and observational charts.

**Table 38: Education monitoring methods in R.O.I..**

	<b>Pre-school n</b>	<b>Primary n</b>	<b>Secondary n</b>	<b>Total n</b>
Staff notes, commentaries	2 (33%)	11 (50%)	-	13 (46%)
Graphs, observation charts	3 (50%)	12 (55%)	-	15 (54%)
Tables	1 (17%)	3 (14%)	-	4 (14%)
BA** supervision	4 (66%)	13 (59%)	-	17 (60%)
Other	-	-	-	-
<b>Total</b>	<b>10 (20%)</b>	<b>39 (80%)</b>	<b>-</b>	<b>49 (100%)</b>

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

*Future day service requirements*

Overall, 65 (65%) children were thought to require different day service provision within the next 5 years (2007-2012), 50 from N.I. and 15 from R.O.I.. For most of the children this will include a change of school, however it also includes 26 children who will no longer require educational provision, 15 from N.I. and 11 from R.O.I.. Future provision for 9 children remains undecided, 7 from N.I. and 2 from R.O.I..

**Table 39: Mode of future day service provision in N.I..**

	<b>Pre-school n</b>	<b>Primary n</b>	<b>Secondary n</b>	<b>Total n</b>
ABA** class	1 (100%)	7 (25%)	4 (29%)	12 (24%)
ABA** school	-	9 (32%)	1 (7%)	10 (20%)
Special needs class	-	6 (21%)	2 (14%)	8 (16%)
Mainstream class	-	1 (4%)	6 (43%)	7 (14%)
Special needs school	-	5 (18%)	1 (7%)	6 (12%)
Adult services	-	-	-	7 (14%)
<b>Total</b>	<b>1 (2%)</b>	<b>28 (56%)</b>	<b>14 (28%)</b>	<b>50 (100%)</b>

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

In N.I., future requirements concerned mainly the need for primary and secondary level ABA education (n=22; 44%) expected to be required for an average of 23-24 hours per week (SD=8.57) including 1:1 support for primary school children and 1:2 support secondary school children. Parents of only one child stated that their child required ABA pre-school education in the future, for 9 hours per week with 1:1 support. Adult services will be required in 7 (14%) cases, for an average of 25 hours per week (SD=10.5) with 1:4 adult:staff ratio (Table 39).



In R.O.I., future requirements concerned mainly the need for ABA education (n=12; 80%) that are expected to be required for an average of 9 hours per week for pre-school and 29 and 37 hours per week for primary (SD=12.5) and secondary school (SD=3.53) children respectively. The expected level of pupil:staff ratio was 1:1 for pre-school, 1:3 for primary and 1:2 for secondary school. Only one person required adult services, for 40 hours per week (Table 40).

**Table 40: Mode of future day service provision in R.O.I..**

	Pre-school n	Primary n	Secondary n	Total n
ABA** class	-	4 (50%)	4 (80%)	8 (53%)
ABA** school	1 (100%)	3 (38%)	-	4 (27%)
Special needs class	-	-	-	-
Mainstream class	-	1 (12%)	1 (20%)	2 (13%)
Special needs school	-	-	-	-
Adult services	-	-	-	1 (7%)
Total	1 (7%)	8 (53%)	5 (33%)	15 (100%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

Collectively for both regions, these data indicate that over the next 3-4 years 88% (n=57) of all future day service requirements are for educational provisions, and 12% (n=8) of children and young people will require some form of adult day service provision. The data also indicate that ABA specific education accounts for 60% (n=34) of all future educational requirements.

The following quotations were obtained during the focus group and reflect the experiences and challenges of the parents seeking educational provisions for their child.

*“Tribunal, tribunal, tribunal.”*

*“Lots of red tape and policies – waste of time. Up to one year spent on choice of school.”*

*“Some support from M.L.As, but only coming up to election time, afterwards M.L.As seem to loose interest again in autism.”*

*“If teachers can’t cope, it’s very stressful as they come back to you. I had difficulty getting occupational therapy and educational psychology to help my child get the right school – two years wasted.”*

*“You need to be prepared to fight for everything. Not enough speech and language. Not enough integration, if your child is in a classroom with other ASD children, how are they meant to learn from peers?”*

*“When my son was 15 years of age, the school gave me a list of places he could go. I checked them out, put his name down. The vice principal said it was all OK. One year later one month before leaving his school, I was informed that school couldn’t take him and I had to look myself.”*

## ASD: Meeting the needs of families

*“Nightmare, don’t know where to begin with this one, he’s bright and at mainstream school but there aren’t the provisions there for him. He is just expected to fit in and he can’t. He’s too bright for special school. Dreading transition to secondary school as there is nothing out there tailored to his needs, very concerned about how his mental health will suffer in secondary school.”*

*“Positive. Moved to a good school at age 11 years of age.”*

*“Knowing not to take NO for an answer, be pushy, and be loud, make yourself heard.”*

*“Child was out of school for 3 years, no contact or investigation from welfare authorities.”*

*“Child has been removed from playgroup/nursery because of challenging behaviour.”*

*“Vice principle said he would make it his job to see that he (i.e., child) was put out of the school. He’s been suspended twice.”*

*“Undertaking a discrimination tribunal, for our child being excluded from school because of his disability.”*

### **Key Points:** Day service provision

- 47% of the parents in N.I. and 54% of the parents in R.O.I., have considered moving their family in order to avail of educational provision that is more appropriate to their child’s needs than what is offered at their present location.
- 8% of the parents have actually moved their families in order to avail of more appropriate educational services for their child, 6% from N.I. and 19% from R.O.I..
- 1 child and 1 young person did not receive any day/educational service.
- In N.I., only 45% of all parents felt their child’s education provision was always appropriate to their needs.
- According to parents in N.I., staff notes and commentaries account for 70% of monitoring methods for educational provision.
- In N.I., only 11% of monitoring methods for the children include science-based methods provided by a behaviour analyst.
- In R.O.I., 60% of monitoring methods for the children include science-based methods provided by a behaviour analyst.
- 69% of children in N.I. and 54% of children in R.O.I. will require a different day service provision within the next five years.
- Collectively: ABA-specific education accounts for 60% of all future educational requirements.
- ABA-specific education accounts for 44% of all future educational requirements in N.I..
- ABA-specific education accounts for 80% of all future educational requirements in R.O.I..

### 11.7 Teacher qualifications: Current and future requirements

Nearly half of the parents (n=43; 47%) did not know the current qualifications of their child's teachers, although most of the others thought that teachers were educated to degree level. There were no teachers who were qualified in ABA in N.I. and only 2 teachers trained to BCBA standard in R.O.I..

28 (38%) parents remained unsure about the type of qualifications required by future teachers of their child, however, nearly half of the parents (n=33; 45%) expected teachers in the future to have some form of ABA training (Table 41).

**Table 41: Current qualifications of teachers and future requirements.**

	Current qualification			Future qualification		
	n	N.I.	R.O.I.	n	N.I.	R.O.I.
Don't Know	43 (47%)	37 (57%)	6 (22%)	28 (38%)	21 (38%)	7 (39%)
Degree	32 (35%)	23 (35%)	9 (33%)	5 (7%)	4 (7%)	1 (5.5%)
Masters	3 (3%)	3 (5%)	-	-	-	-
ASD Masters	2 (2%)	2 (3%)	-	7 (10%)	5 (9%)	2 (11%)
ABA Masters	5 (6%)	-	5 (19%)	11 (15%)	10 (18%)	1 (5.5%)
ABA PhD	4 (4%)	-	4 (15%)	2 (3%)	1 (2%)	1 (5.5%)
BCABA*	1 (1%)	-	1 (4%)	3 (4%)	2 (4%)	1 (5.5%)
BCBA	2 (2%)	-	2 (7%)	17 (23%)	12 (22%)	5 (28%)
Total	92 (100%)	65 (71%)	27 (29%)	73 (100%)	55 (75%)	18 (25%)

\*From Jan 2009 – BCaBA

Most of the parents (n=62; 80%) did not know the current qualifications of their child's teaching assistants including whether or not they had any training in ASD. There were no ABA-trained teaching assistants in N.I. and only one BCABA-trained teaching assistant in R.O.I.. Half of the parents were unsure about future training needs for teaching assistants, although the other 26 (40%) parents stated that some form of ABA educational attainment was required by education assistants in the future (Table 42).

**Table 42: Current qualifications of teaching assistants and future requirements.**

	Current qualification			Future qualification		
	n	N.I.	R.O.I.	n	N.I.	R.O.I.
Don't Know	62 (80%)	51 (92%)	11 (52%)	31 (48%)	23 (48%)	8 (47%)
Degree	6 (8%)	1 (2%)	5 (24%)	5 (8%)	2 (4%)	3 (18%)
Master	-	-	-	-	-	-
ASD Masters	-	-	-	2 (3%)	2 (4%)	-
ABA Masters	-	-	-	5 (8%)	4 (9%)	1 (6%)
ABA PhD	-	-	-	-	-	-
BCABA*	1 (1%)	-	1 (5%)	18 (28%)	15 (31%)	3 (18%)
BCBA	-	-	-	3 (3%)	2 (4%)	1 (6%)
Other	8 (11%)	4 (7%)	4 (19%)	1 (2%)	-	1 (6%)
Total	77 (100%)	56 (73%)	21 (27%)	65 (100%)	48 (74%)	17 (26%)

\*From Jan 2009 – BCaBA.

Nearly half of the parents did not know if teachers had received continuous professional development (CPD) training, the remainder of the parents thought that teachers had received short-term ASD-specific or ABA-specific CPD training either in from of conferences or workshops, short courses, and/or through 1:1 supervision by a qualified behaviour analyst (Table 43).

**Table 43: Current CPD training of teachers.**

	Conference/workshops		
	n	N.I.	R.O.I.
Don't Know	45 (48%)	38 (60%)	7 (25%)
Training in ASD	22 (24%)	18 (28%)	4 (6%)
Training in ABA	16 (17%)	4 (14%)	12 (43%)
Other	-	-	-
	Short courses		
Don't Know	42 (45%)	35 (54%)	7 (25%)
Training in ASD	27 (29%)	22 (39%)	5 (18%)
Training in ABA	13 (14%)	5 (8%)	8 (29%)
Other	3 (3%)	1 (2%)	2 (7%)
	1:1 supervision by BA**		
Don't Know	46 (50%)	39 (60%)	7 (25%)
Training in ASD	5 (5%)	4 (6%)	1 (4%)
Training in ABA	18 (19%)	4 (6%)	14 (50%)
Other	-	-	-
Total	93 (100%)	65 (70%)	28 (30%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

All of the parents thought that in future teachers should receive additional CPD training in ASD and/or ABA either in from of conferences or workshops, short courses, and/or through 1:1 supervision by a qualified behaviour analyst (Table 44).

**Table 44: Future CPD training needs of teachers.**

	Conference/workshops		
	n	N.I.	R.O.I.
Training in ASD	54 (56%)	45 (65%)	9 (35%)
Training in ABA	58 (61%)	46 (68%)	12 (46%)
Other	3 (3%)	1 (1%)	2 (8%)
	Short courses		
Training in ASD	50 (53%)	42 (61%)	8 (31%)
Training in ABA	54 (57%)	44 (64%)	10 (38%)
Other	-	-	-
	1:1 supervision by BA**		
Training in ASD	46 (48%)	43 (63%)	3 (12%)
Training in ABA	54 (57%)	45 (65%)	9 (35%)
Other	-	-	-
Total responses	95 (100%)	69 (73%)	26 (27%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

Two-thirds of the parents did not know if education assistants had received CPD training, the remainder of the parents thought that education assistants had received either ASD-specific and/or ABA-specific CPD training either in form of conferences or workshops, short courses, through 1:1 supervision by a qualified behaviour analyst, and/or other (Table 45).

**Table 45: Current CPD training of education assistants.**

	Conference/workshops		
	n	N.I.	R.O.I.
Don't Know	28 (30%)	25 (38%)	3 (11%)
Training in ASD	12 (13%)	12 (18%)	-
Training in ABA	13 (14%)	6 (9%)	7 (25%)
Other	1 (1%)	1 (2%)	-
	Short courses		
Don't Know	27 (29%)	24 (37%)	3 (11%)
Training in ASD	16 (17%)	14 (21%)	2 (7%)
Training in ABA	16 (17%)	8 (12%)	8 (29%)
Other	-	-	-
	1:1 supervision by BA**		
Don't Know	27 (29%)	24 (37%)	3 (11%)
Training in ASD	4 (4%)	4 (6%)	-
Training in ABA	14 (15%)	4 (6%)	10 (36%)
Other	-	-	-
Total responses	93 (100%)	65 (70%)	28 (30%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

**Table 46: Future CPD training needs of education assistants.**

	Conference/workshops		
	n	N.I.	R.O.I.
Training in ASD	51 (54%)	44 (64%)	7 (27%)
Training in ABA	57 (60%)	43 (62%)	13 (50%)
Other	2 (2%)	1 (1%)	1 (4%)
	Short courses		
Training in ASD	48 (51%)	41 (60%)	7 (27%)
Training in ABA	51 (54%)	42 (61%)	9 (35%)
Other	-	-	-
	1:1 supervision by BA**		
Training in ASD	46 (48%)	43 (63%)	3 (12%)
Training in ABA	54 (57%)	44 (64%)	10 (38%)
Other	-	-	-
Total responses	95 (100%)	69 (73%)	26 (27%)

\*\*Provided by qualified behaviour analyst – trained to BCBA/PhD level.

All of the parents thought that education assistants should receive CPD training in ASD and/or ABA either in form of conferences or workshops, short courses, and/or through 1:1 supervision by a qualified behaviour analyst (Table 46).

Parents described in the focus group the areas in which greater support is needed:

*“ABA schools.”*

*“Greater interaction, speech therapy, classroom assistants, should be more readily available with more money put in place for ABA schools.”*

*“Adequate schooling with small class sizes and ABA provision.”*

*“Schools need ABA provisions both in mainstream and special needs.”*

*“Appropriately trained professionals to deliver training.”*

*“Training for teachers and classroom assistances in ABA.”*

**Key Points:** Teacher & education assistants’ qualifications and training requirements.

- 47% of the parents did not know what type of qualifications were held by the teachers currently educating their child, 57% in N.I. and 22% in R.O.I..
- In N.I. parents thought that none of the teachers had any form of ABA training.
- 45% of the parents thought that teachers required ABA training in the future.
- 80% of the parents did not know the qualifications of the child’s education assistants.
- In N.I. parents thought that none of the teacher assistants had any form of ABA or ASD training.
- 40% of the parents thought that teaching assistants require some form of ABA in the future; 31% require BCABA (BCaBA).
- 48% of the parents did not know if their child’s teacher had received CPD training in conferences or workshops.
- In the future, 56% of the parents thought that teachers require CPD conferences or workshop training in ASD, and 61% require CPD training in ABA.
- 45% of the parents did not know if their child’s teacher had received CPD training in short courses.
- In the future, 53% of the parents thought that teachers require additional CPD short course training in ASD, 57% require additional training in ABA.
- 50% of the parents did not know if their child’s teacher had received 1:1 supervision from a behaviour analyst.
- In the future, 48% of the parents thought that teachers require 1:1 supervision from a qualified behaviour analyst in ASD, 57% of teachers require 1:1 supervision from a qualified behaviour analyst in ABA.
- 30% of the parents did not know if their child’s educational assistant had received CPD training in conferences or workshop.
- In the future, 54% of the parents thought that educational assistants requiring CPD conference or workshop training in ASD, 60% require additional training

in ABA.

- 29% parents did not know if their child's educational assistant had received CPD training in short courses.
- In the future, 51% of the parents thought that educational assistants require short course CPD training in ASD, 54% require additional training in ABA.
- 29% of the parents did not know if their child's educational assistant had received 1:1 supervision from a qualified behaviour analyst.
- In the future, 48% of the parents thought that educational assistants require 1:1 supervision from a qualified behaviour analyst in ASD, 57% require 1:1 supervision from a qualified behaviour analyst in ABA.

## 11.8 Financial support

Nearly half of the parents (n=40; 44%) had not been informed by statutory services about available financial support (Table 15). Most parents who knew about financial support availed of it to some extent (n=59; 72%), 43 (67%) from N.I. and 16 (89%) from R.O.I. (Table 47). 44 (66%) professionals had noted that parents experienced significant distress when seeking funding to support their children's educational provision.

**Table 47: Current financial support for children.**

Nature of support	Total	N.I.		R.O.I.	
	n	n	Received	n	Received
FT home tuition fees	88	60	-	28	-
Part of home tutor fees	88	60	1 (2%)	28	1 (4%)
Transport costs	93	65	23 (35%)	28	17 (61%)
Medical card	93	65	8 (12%)	28	18 (64%)
Disability allowance	95	67	61 (91%)	28	8 (29%)
Mobility allowance	94	66	25 (38%)	28	1 (4%)
Direct payment	92	64	6 (9%)	28	22 (79%)
Other	100	72	2 (3%)	28	3 (11%)

In N.I., none of the parents were in receipt of full-time home tuition fees for their child and only one parent stated that they received any help with payments for home tutors. Mainly, financial support was received in relation to disability allowance, on average £3,000 per annum (based on 6 responses); transport costs, on average £933 per annum (based on 5 responses); direct payments for respite care, £3,840 per annum (based on one response); and other financial supports such as incapacity benefit, an average of £3,500 per annum (based on 2 responses).

Education and Library Boards provided financial support to 20 (28%) children, an average of £2,245 per annum (based on 3 responses). Health and Social Services provided financial support to 56 children, an average of £3,162 per annum (based on 25 responses). No child was in receipt of financial support from other agencies.

In R.O.I. none of the parents were in receipt of full-time home tuition fees and only one parent received help with home tuition of €9,000 per annum. Mainly, financial help was received in relation to direct payments for respite care, on average €1,225 per annum (based on 12 responses); transport costs, on average €5,333 per annum (based on 3 responses); medical card, on average €1,080 per annum (based on 2 responses); disability



allowance, on average €1,589 per annum (based on 4 responses); mobility allowance, €280 per annum (based on one responses); and other financial supports, such as respite grants for siblings, on average €3,333 per annum (based on 3 responses).

The Department of Education and Science provided financial support to 22 (79%) children, on average €35,000 per annum (based on 3 responses). The Health Service Executive (HSE) provided financial support to 23 (82%) children, on average €10,071 per annum (based on 8 responses). No child was in receipt of financial support for other agencies.

#### *Future financial support required*

64 (64%) parents reported that children require financial supports in the future, 44 from N.I. and 20 from R.O.I., most of which is needed immediately (2007-2008) (Table 48).

**Table 48: Future financial support needs.**

		N.I.		R.O.I.	
	n	n	Required	n	Required
FT home tuition fees	54	35	5 (14%)	19	3 (16%)
Part of home tutor fees	55	37	12 (32%)	18	5 (29%)
Transport costs	59	39	21 (54%)	20	17 (85%)
Medical card	57	36	6 (17%)	21	15 (71%)
Disability allowance	62	42	37 (88%)	20	10 (50%)
Mobility allowance	56	39	22 (56%)	17	2 (8%)
Direct payment	57	36	7 (19%)	21	19 (90%)
Other	54	37	1 (4%)	13	4 (23%)

In N.I., future financial support needs include full-time home tuition fees, approximately £25,000 per annum (based on one response); part of home tuition fees, on average £8,166 per annum (based on 3 responses); transport costs of approximately £1,000 per annum (based on 2 responses); medical card; disability allowance, on average £3,394 per annum (based on 15 responses); mobility allowance, on average £6,500 (based on 3 responses); direct payment; and other financial supports, e.g., one child required third level education grant of £5,000 per annum.

20 (29%) children required future financial support from Education and Library Boards and 56 (78%) children require financial support from Health and Social Services, on average £2,946 per annum (based on 9 responses).

In R.O.I., future financial support needs include full-time home tuition fees; part of home tutor fee, on average €15,000 per annum (based on 3 responses); transport costs, on average €1,180 per annum (based on 5 responses); medical card, on average €1,280 per annum (based on 2 responses); disability allowance, on average €2,400 per annum (based on 2 responses); mobility allowance, of approximately €2,000 (based on one response); direct payment in respect of respite care, on average €1,544 per annum (based on 9 responses); and other financial supports, such as respite grants for siblings on average €10,000 per annum (based on 3 responses).

16 children (29%) require future financial support from the Department of Education and Science, on average €26,250 per annum (based on 6 responses); 17 children require



financial support from Health Service Executive (HSE), on average €3,714 per annum (based on 5 responses).

The following quotations from the focus group and reflect the experiences of the parents seeking financial support for their child:

*“Takes a long time, information is held back and misleading.”*

*“Got help from Family Fund. I had to take a career break.”*

*“I have just finished re-applying for Disability Living Allowance (DLA). The forms took me 6 week to complete, why does it have to be such a long winded process, when your child has been diagnosed with having a life long illness?”*

*“Hard to find out what’s available, how do you get Direct Payments, for example?”*

*“He had his DLA reduced, don’t know why, as he’s worse since the first application and comparing applications confirms this. Being a single parent in full-time work, I didn’t feel I had the time, strength and support to fight the decision.”*

*“All hard work, but there is very little financial support out there.”*

*“No matter what we asked for, we didn’t get a thing.”*

*“Had to re-mortgage my home, to raise funds to support my child’s home programme.”*

*“Will I record, what I will get in reality, or will I record what I actually need.”*

#### **Key Points:** Financial supports

- 44% of the parents were not informed by statutory services about financial support available to their child and family.
- No child was in receipt of full-time home tuition fees; only two children were in receipt of financial support to cover some of the home tutor fees.
- In N.I., 9% of children were in receipt of direct payments for respite care.
- In R.O.I., 79% of children were in receipt of direct payments for respite care.

#### **In future:**

- 14% of children in N.I. require full-time home tuition fees.
- 32% of children in N.I. require home tutor fees.
- 16% of children in R.O.I. require full-time home tuition fees.
- 29% of children in R.O.I. require home tutor fees.
- 19% of children in N.I. require direct payment in respect of respite care.
- 90% of children in R.O.I. require direct payment in respect of respite care.

### 11.9 Multi-disciplinary support and therapy (MDT)

37 (42%) parents were not informed by statutory services about multi-disciplinary support and therapy (MDT) available to their family, 25 from N.I. and 12 from R.O.I. (based on 88 responses). 53 (56%) parents stated that they would avail of MDT services once they knew about them. 70 (71%) children received on average 3 different MDT services (SD=1.6), 53 from N.I. and 17 from R.O.I., while 28 (29%) children did not receive any MDT (Table 49).

**Table 49: Current MDT services.**

	<b>N.I.</b>		<b>R.O.I.</b>	
<b>MDT service received</b>	<b>n =71*</b>	<b>h/m (n)**</b>	<b>n=27*</b>	<b>h/m (n)**</b>
S & L*** therapist	40 (56%)	2.2 (27)	16 (60%)	4.8 (9)
Occupational therapist	21 (30%)	1.9 (17)	14 (52%)	3.3 (8)
Behaviour analyst****	20 (28%)	2.8 (16)	4 (15%)	2.5 (2)
Social worker	18 (25%)	1.0 (2)	4 (15%)	1.0 (2)
Educational psychologist	8 (11%)	- (0)	3 (11%)	1.0 (1)
Clinical psychologist	7 (10%)	1.0 (1)	2 (7%)	- (0)
Autism therapist	6 (9%)	4.6 (3)	1 (4%)	- (0)
Medical services	6 (9%)	1.0 (1)	4 (15%)	1.0 (1)
Physiotherapist	5 (7%)	2.8 (4)	3 (11%)	8.0 (1)
Nurse	1 (1%)	- (0)	1 (4%)	- (0)
Psychiatrist	1 (1%)	- (0)	1 (4%)	- (0)
None	18 (36%)		10 (37%)	

\*Data missing (n=1).

\*\* Average hours/month (number of responses available for calculation).

\*\*\*Speech and language.

\*\*\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

NB: Occupational therapist: Outlying data excluded (30 hours per month for one child).

In N.I., statutory MDT services came from speech and language therapists, occupational therapists, and social workers; applied behaviour analysis was provided by a local charity (PEAT). In R.O.I., most statutory MDT came from speech and language therapists and occupational therapists; applied behaviour analysis was provided by ABA schools.

Over two thirds of the professionals had noticed that parents experienced distress when trying to access MDT, in particular occupational therapy, speech and language therapy, clinical and educational psychology, autism therapy, and behaviour analysis (Table 50).

**Table 50: Professional perception of parental distress regarding MDT services.**

	Total	N.I.	R.O.I.
	n=47	n=21	n=46
Noticed parental distress			
Occupational therapist	47 (70%)	13 (62%)	34 (74%)
S & L** therapist	46 (68%)	11 (52%)	35 (76%)
Clinical psychologist	45 (67%)	12 (57%)	33 (72%)
Educational psychologist	40 (59%)	9 (43%)	31 (67%)
Autism therapist	39 (58%)	9 (43%)	30 (65%)
Behaviour analyst***	36 (54%)	6 (29%)	30 (65%)
SEN teacher	29 (43%)	7 (33%)	22 (48%)
Psychiatrist	27 (40%)	5 (24%)	22 (49%)
Social worker	22 (33%)	6 (29%)	16 (35%)
Physiotherapist	19 (28%)	2 (10%)	17 (37%)
Paediatrician	17 (25%)	7 (33%)	10 (22%)
Medical services (GP)	16 (24%)	4 (19%)	12 (26%)
Nurse	15 (22%)	1 (5%)	14 (30%)
Mental health nurse	13 (19%)	3 (14%)	10 (22%)
Public health Nurse	12 (18%)	1 (5%)	11 (24%)
Other	3 (4%)	1 (5%)	2 (4%)

\*\*S &amp; L = Speech and language.

\*\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

**Table 51: Professional assessment of appropriate package of MDT support.**

	Total	N.I.	R.O.I.
	n=67	n=21	n=46
MDT service			
S & L** therapist	60 (89%)	17 (81%)	43 (93%)
Occupational therapist	58 (86%)	16 (76%)	42 (91%)
Clinical psychologist	54 (80%)	18 (86%)	36 (78%)
Educational psychologist	51 (76%)	15 (71%)	36 (78%)
Behaviour analyst***	49 (73%)	12 (57%)	37 (80%)
SEN teacher	50 (74%)	16 (76%)	34 (74%)
Autism therapist	49 (73%)	17 (81%)	32 (70%)
Social worker	43 (64%)	15 (71%)	28 (61%)
Paediatrician	41 (62%)	14 (67%)	27 (59%)
Psychiatrist	34 (51%)	6 (29%)	28 (61%)
Learning disability nurse	31 (46%)	9 (43%)	22 (48%)
Medical services (GP)	25 (37%)	5 (24%)	20 (43%)
Physiotherapist	23 (34%)	5 (24%)	18 (39%)
Public health nurse	17 (25%)	-	17 (37%)
Mental health nurse	10 (15%)	1 (5%)	9 (20%)
Other	5 (7%)	1 (5%)	4 (9%)

\*\*S &amp; L = Speech and language.

\*\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

Overall, professionals considered an appropriate package of MDT support to include an average of 9 different MDT services (SD=3.5) (Table 51).

#### *Future MDT requirements*

71 (71%) children required MDT supports in the future. 21 of these children did not previously avail of these supports, 12 from N.I. and 9 from R.O.I..

69 parents gave details of the kinds of MDT required by their child, 51 from N.I. and 18 from R.O.I.. Overall, the average number of MDT supports required per children was 4 (SD=2.06) (Table 52).

**Table 52: Future MDT support requirements.**

	<b>N.I.</b>		<b>R.O.I.</b>	
<b>MDT services required</b>	<b>n=51</b>	<b>h/m (n)**</b>	<b>n=18</b>	<b>h/m (n)**</b>
S & L*** therapist	41 (80%)	10 (32)	13 (72%)	9 (10)
Behaviour analyst****	37 (73%)	12 (28)	11 (61%)	6 (8)
Occupational Therapist	32 (63%)	8 (20)	17 (94%)	10 (14)
Autism Therapist	24 (47%)	11 (16)	7 (39%)	10 (6)
Social Worker	21 (41%)	3 (9)	7 (29%)	6 (6)
Educational Psychologist	14 (27%)	2 (6)	10 (55%)	2 (7)
Clinical Psychologist	10 (20%)	1 (4)	8 (44%)	6 (6)
Medical Services	9 (18%)	2 (2)	7 (39%)	2 (6)
Physiotherapist	7 (14%)	9 (4)	6 (33%)	9 (6)
Nurse	2 (4%)	-	-	-
Psychiatrist	1 (2%)	-	-	-
Other	5 (10%)	6 (1)	-	-

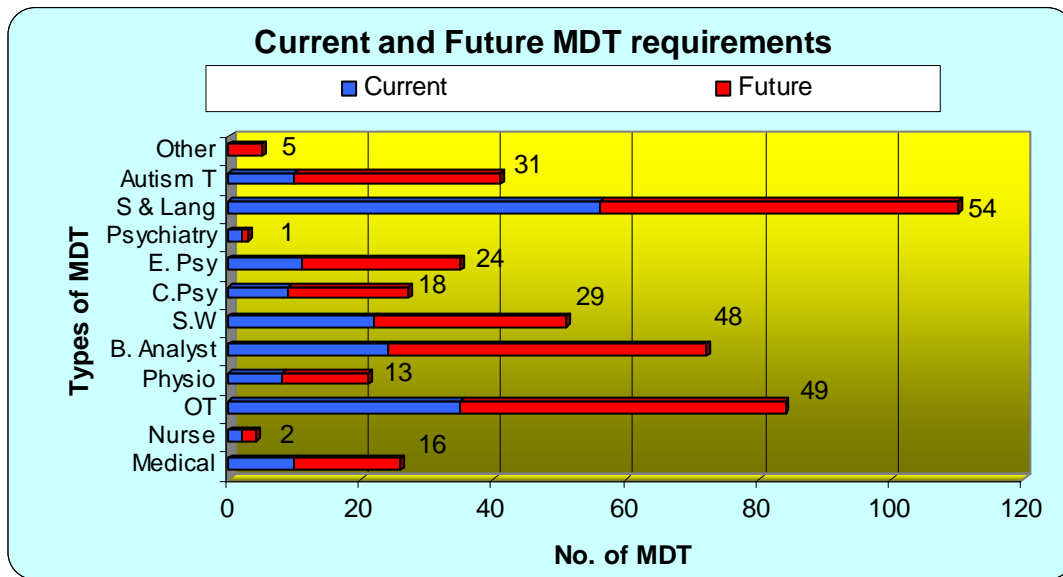
\*\* Average hours/month (number of responses available for calculation).

\*\*\*Speech and language.

\*\*\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

Figure 6 illustrates the types of MDT services currently received and indicates future requirements for MDT support.

**Figure 6: Current and future MDT requirements**



The following quotations were obtained during the focus group and reflect the views and experiences of the parents seeking multi-disciplinary support and therapy:

*“Have not been informed of any.”*

*“Services are very fragmented with little or no coherence. Went 2 years without a social worker, didn’t know I was entitled to one until another parent told me and then I had to chase up.”*

*“Part of the team does not work as a team with us.”*

*“We wouldn’t need MDT support if our child was getting ABA in school.”*

*“No information provided for example on Direct Payments and waiting lists for OT [occupational therapy]”*

*“Services don’t address the needs or deficits of a child.”*

*“Positive: Autism team, OT, teachers and psychiatrist. Brought me and my husband closer together.”*

*“Meeting the very few professional people who truly understand what you need as a family has only happened through PEAT.”*

*“Professionals talk to me as through I have no sense, very patronising.”*

**Key Points:** Multi-disciplinary support and therapy (MDT)

- 42% of the parents were not being informed by statutory services of the multi-disciplinary services available to their family.
- Professionals noted that parents were experiencing significant distress or

difficulties seeking MDT support.

- Professionals identified 9 MDT services as defining an appropriate package of MDT support.
- The majority of the professionals defined an appropriate package of MDT support as involving a speech and language therapist (89%), occupational therapist (86%), clinical psychologist (80%), educational psychologist (76%), behaviour analyst (73%), special education needs teachers (74%), autism therapist (73%), social worker (64%), and a paediatrician (62%).
- 71 % of children were in receipt of an average of 3 MDT services.
- 29% children were not in receipt of any MDT supports.

#### Future need in N.I.

- 80% of children require a speech and language therapist, on average 10 hours per month.
- 63% of children require occupational therapy, on average 8.3 hours per month.
- 73% of children require a behaviour analyst, on average 12 hours per month.
- 41% of children require a social worker, on average 3 hours per month.
- 47% of children require an autism therapist, on average 11 hours per month.

#### Future need in R.O.I.

- 72% of children require a speech and language therapist, on average 9 hours per month.
- 94% of children require occupational therapy, on average 10 hours per month.
- 61% of children require a behaviour analyst, on average 6 hours per month.
- 55% of children require an educational psychologist, on average 2 hours per month.
- 39% of children require a social worker, on average 6 hours per month.
- 39% of children require an autism therapist, on average 10 hours per month.
- 44% of children require a clinical psychologist, on average 6 hours per month.

### **11.10 Home and respite support**

44 (48%) parents had not being informed by statutory services about home and respite supports available to their family, 34 in N.I. and 10 in R.O.I.. 36 (38%) of the parents were in receipt of home and respite support, 24 in N.I. and 12 in R.O.I..

49 (73%) professionals noted that parents experienced significant distress or difficulties when trying to access home supports, 16 in N.I. and 33 in R.O.I.. 55 (82%) professionals noted that parents had experienced significant distress or difficulties when trying to access residential and respite support, 17 in N.I. and 38 in R.O.I..

#### *Current home and family support*

22 (24%) families were in receipt of home and family support, 9 in N.I. and 13 in R.O.I. The main support was in direct payments used to purchase home and family support (Table 53).

**Table 53: Current home and family support.**

	N.I.		R.O.I.	
n=22	n=9	h/m (n)*	n=13	h/m (n)*
Domiciliary help	1 (1%)	4 (1)	7 (28%)	19 (5)
Family support	3 (4%)	14 (3)	8 (32%)	18 (7)
Direct payments	5 (7%)	23 (4)	2 (8%)	16 (2)

\*Average hours/month (number of responses available for calculation).

15 (68%) parents felt the home and family support sometimes met the needs of their child; one parent from R.O.I. felt that home support always meet their child's needs, and 6 parents felt the home support never met their child's needs.

#### *Future home and family support requirements*

47 (50%) families required home and family support in the future, 31 in N.I. and 16 in R.O.I. (Table 54). 29 (62%) of these families were not in receipt of these services currently; most of the services (83%) were required immediately.

**Table 54: Future home and family support needs.**

	N.I.		ROI	
n=47	n=31	h/m (n)*	n=16	h/m (n)*
Domiciliary help	18 (55%)	15 (17)	8 (50%)	21 (7)
Family support	20 (61%)	13 (19)	10 (67%)	28 (10)
Direct payments	24 (71%)	16 (22)	6 (46%)	21 (6)

\*Average hours/month (number of responses available for calculation).

#### *Current respite support services*

32 (33%) children were in receipt of respite support, 23 from N.I. and 9 from R.O.I. (Table 55).

**Table 55: Current respite support services.**

	N.I.		ROI	
n=32	n=23	h/m (n)*	n=9	h/m (n)*
Out-of-home respite	6 (8%)	14 (3**)	6 (21%)	10 (4**)
In-home respite	5 (7%)	12 (5)	2 (7%)	20 (2)
Home-to-home scheme	5 (7%)	15 (3**)	-	-
Holiday club	8 (11%)	26 (6)	1 (4%)	40 (1)
After-school club	7 (10%)	14 (7)	-	-

\*Average hours/month (number of responses available for calculation).

\*\*Data excluded (n=3) due to outlying data (72, 96, and 54 hours per month).

21 (84%) parents felt the respite supports sometimes met the needs of their child, 3 parents all from N.I. felt the respite support always met their child's needs, and one parent from N.I. felt respite provision never met their child's needs.

#### *Future respite support service requirements*

52 (52%) children required respite support services in the future. 37 in N.I. and 15 in R.O.I. (Table 56). 31(60%) of these children were not in receipt of respite support service currently, 22 in N.I. and 9 in R.O.I. Most of these services (75%) were required immediately.

**Table 56: Future respite support service requirements.**

	N.I.		R.O.I.	
n=52	n=37	h/m (n)*	n=15	h/m (n)*
Out-of-home respite	8 (22%)	20 (6)	8 (53%)	34 (7**)
In-home respite	16 (43%)	15 (14)	9 (60%)	29 (7)
Home-to-home scheme	7 (19%)	20 (6**)	-	-
Holiday club	22 (59%)	24 (17)	10 (67%)	33 (7**)
After-school club	21 (57%)	16 (15)	9 (60%)	16 (7)

\*Average hours/month (number of responses available for calculation).

\*\*Data excluded (n=3) due to outlying data (96 and 120 hours per month).

The following quotations were obtained during the focus group and reflect the views and experiences of the parents seeking home and family and respite support for their children and families:

*“Dreadful, made to feel inferior by even seeking it.”*

*“If we don’t know the questions to ask, then we don’t get any answers. Social services should be called secret services.”*

*“When I asked for respite, Social worker refused as my child’s IQ was below average (i.e., too high). I highlighted that my child’s IQ was deteriorating, educational psychologist refused to check. When her IQ was checked a year later, she had severe learning disability.”*

*“Lack of experienced staff in the respite centre.”*

*“Our local respite manager was very supportive and offering us respite for now.”*

*“We receive direct payments and it works really well for me and my children.”*

#### **Key points: Home, family and respite support services**

- 48% parents were not being informed by statutory services about the types of home and respite supports available to their family.
- 73% of the professionals noted parents experiencing significant distress when trying to access home supports.
- 82% of the professionals noted parents experiencing significant distress when trying to access residential and respite supports.
- 24% of families were in receipt of home and family support.
- 33% of children were receipt of respite support.
- Only 3 parents from N.I. and one parent from R.O.I. felt that home support *always* meet their child’s needs.
- Only 4 parents in N.I. and 5 in R.O.I. received home support services and respite support services.
- In the future, 61% of families will require home supports; 55% of families will require domiciliary care, 51% of children will require respite supports.



- 94% of future home and family support requirements will be from families not in receipt of those services currently.

### 11.11 Additional support from non-statutory services

In addition to statutory supports, 69 (75%) parents were seeking additional non-statutory supports for their family (Table 57).

**Table 57: Additional non-statutory home and family support.**

	N.I.		R.O.I.	
n=69	n=56	h/m (n)*	n=13	h/m (n)*
Extended family	46 (82%)	28 (36)	13 (100%)	16 (9)
Friends	10 (18%)	5 (4)	5 (38%)	6 (3)
Voluntary organisations	22 (39%)	6 (19)	1 (8%)	-

\*Average hours/month (number of responses available for calculation).

The 39 (42%) parents and families who were not receiving any form of statutory home, family, or respite support relied particularly heavily on non-statutory supports from extended family and friends and voluntary agencies (Table 58).

**Table 58: Sole home and family supports.**

	N.I.		R.O.I.	
n=39	n=33	h/m (n)*	n=6	h/m (n)*
Extended family	29 (88%)	31 (23)	6 (100%)	18 (3)
Friends	5 (15%)	5 (2)	3 (50%)	1 (1)
Voluntary Organisations	12 (36%)	3 (11)	-	-

\*Average hours/month (number of responses available for calculation).

#### **Key points:** Non-statutory supports

- 75% of all parents were seeking additional non-statutory supports for their family, 81% of families in N.I..
- 46 families in N.I. who were receiving statutory supports were also receiving an average of 28 hours per month support from their extended family.
- 42% families were not receiving any form of home support or respite support.
- 48% of families in N.I. not in receipt of any statutory home or respite supports were seeking additional support.

### 11.12 Care plans

80 (83%) children had an individual care or education plan, 54 from N.I. and 26 from R.O.I.. 12 (17%) children from N.I. did not have any care plan, 3 of these children were attending pre-school, 4 primary school, and 3 secondary school (Table 59).

**Table 59: Current individual care and education plans.**

	<b>N.I. n=54</b>		<b>R.O.I. n=26</b>	
<b>n=80</b>	<b>Plan</b>	<b>No plan</b>	<b>Plan</b>	<b>No plan</b>
PCP*	9 (17%)	37 (68%)	1 (4%)	20 (77%)
IEP**	52 (96%)	2 (4%)	26 (100%)	-
Other	1 (2%)	-	-	-
Don't know	8 (15%)	-	6 (19%)	-

\*PCP=Person centred plan.

\*\*IEP=Individual education plan.

*Review of care plans*

In N.I., care and education plans were reviewed on average every 9 months (SD=3.80) (based on 40 responses), 10 parents did not know how often their child's care plan was reviewed. 24 parents felt that their child's care plan was sometimes appropriate, 16 parents felt that the care plans were always appropriate, 4 felt their child's care plan was never appropriate to their child's needs, and one parent was unsure.

In R.O.I., education plans were reviewed on average every 8 months (SD=3.23) (based on 19 responses). 10 parents felt that the care plans were always appropriate, 8 felt that their care plan was sometimes appropriate, 2 felt their child's care plan was never appropriate to their child's needs, and one was unsure. A wide range of the professionals were involved in the review of care and education plans (Table 60).

**Table 60: Professionals involved in review of care and education plans.**

<b>Professionals involved</b>	<b>N.I. n=52</b>	<b>R.O.I. n=22</b>
Teacher	48 (92%)	14 (64%)
S & L therapist*	25 (48%)	11 (50%)
Occupational therapist	14 (27%)	11 (50%)
Educational psychologist	11 (21%)	6 (27%)
Autism therapist	8 (15%)	-
Physiotherapist	6 (12%)	3 (14%)
Social worker	7 (13%)	2 (9%)
Behaviour analyst**	5 (10%)	15 (68%)
Nurse	3 (6%)	2 (9%)
Psychiatrist	1 (2%)	-
Clinical psychologist	-	2 (9%)
Other	3 (6%)	2 (9%)

\*Speech and language.

\*\*Qualified behaviour analyst – trained to BCBA/PhD level.

The average number of the professionals involved in the review of a care or education plan was 3 (SD=1.44 in N.I. and SD=1.73 in R.O.I.). 70 parents had always or sometimes been invited to participate in the review of their child's care and education plan, 9 N.I. parents had never been invited to take part in the review (Table 61).

**Table 61: Invitations to participate in review of care and education plans.**

Parents invited	n=79	N.I. n=54	R.O.I. n=22
Always	57 (72%)	38 (70%)	19 (86%)
Sometimes	10 (13%)	7 (13%)	3 (14%)
Never	9 (12%)	9 (17%)	-

The vast majority of the parents who were invited to attend review meetings always agreed to participate in reviewing their child's care and education plans (Table 62).

**Table 62: Accepting invitations to take part in review of care and education plans.**

Parent accept invitation	n=65	N.I. n=44	R.O.I. n=21
Always	63 (97%)	42 (96%)	21 (100%)
Sometimes	2 (3%)	2 (4%)	-
Never	-	-	-

Only half of the parents who attended review meetings felt that their choices and opinions were included as part of the care plan review, 5 N.I. parents felt that their views and choices were never included in their child's care and education plans (Table 63).

**Table 63: Inclusion of parental choices and opinions in care and education plans.**

Choices/opinions included	n=62	N.I. n=42	R.O.I. n=20
Always	31 (50%)	22 (52%)	9 (45%)
Sometimes	26 (42%)	15 (36%)	11 (55%)
Never	5 (8%)	5 (12%)	-

Less than half of the parents had been told what monitoring methods were used to determine when targets and objectives of care plans had been met. One third of the parents had never been told what monitoring methods were used were unsure (Table 64).

**Table 64: Monitoring of care and education plans.**

Monitoring methods explained	n=62	N.I. n=42	R.O.I. n=20
Always	25 (40%)	17 (40%)	8 (40%)
Sometimes	17 (28%)	9 (21%)	8 (40%)
Never	15 (24%)	12 (29%)	3 (15%)
Don't know	5 (8%)	4 (10%)	1 (5%)

Two thirds of reviews were conducted without regular use of data displays, such as graphs or charts, to monitor progress of the child; in nearly half of the reviews data displays were never used, or parents were unsure (Table 65).

**Table 65: Use of data graphs or charts in care plan reviews.**

Data graphs/charts used	n=51	N.I. n=34	R.O.I. n=17
Always	16 (31%)	9 (27%)	7 (41%)
Sometimes	14 (28%)	8 (24%)	6 (35%)
Never	18 (35%)	15 (44%)	3 (18%)
Don't Know	3 (6%)	2 (5%)	1 (6%)

For the most part, data that had been collected during home tuition was not considered during the reviews of care and education plans that were attended by parents (Table 66).

**Table 66: Consideration of data from home tuition programmes during reviews.**

Home tuition data considered	n=31	N.I. n=28	R.O.I. n=3
Always	6 (19%)	5 (18%)	1 (33%)
Sometimes	9 (29%)	8 (29%)	1 (33%)
Never	13 (42%)	12 (43%)	1 (33%)
Don't Know	3 (10%)	3 (10%)	-

**Key Points:** Care and education plans.

- 83% of children had a care or education plans.
- 74% of these plans were reviewed on average every 8-9 months.
- 19% of the parents did not know how often their child's plan was reviewed.
- 53% of the parents in N.I. felt their child's plan was *sometimes* appropriate.
- 48% of the parents in R.O.I. felt their child's plans were *always* appropriate to their child's needs.
- 16% of children in N.I. attending school did not have an education plan.
- An average of 3 professionals were involved in the review of plans.
- 10% of care plan reviews in N.I. and 68% of reviews in R.O.I. included a behaviour analyst.
- 21% of children's plan reviews in N.I. (27% in R.O.I.) included an educational psychologist.
- None of the reviews in N.I. (9% in R.O.I.) included a clinical psychologist.
- 17% of the parents from N.I. were *never* invited to the review of their child's plan; all parents in R.O.I. were invited at least sometimes.
- 48% of the parents who attended reviews in N.I. felt their opinions and choices were only *sometimes* or *never* included in the review process; all parents in R.O.I. felt their views were included at least sometimes.
- 60% of the parents who attended reviews in N.I. (40% in R.O.I.) did not have monitoring methods explained fully.
- 73% of the parents who attended reviews in N.I. did not see monitoring methods being used consistently; 27 % in R.O.I. always saw the inclusion of monitoring data during the review process.
- 78% of home tuition programmes in N.I. were monitored. These data were considered in only 18% of care and education plan reviews.

### 11.13 Child behaviours that cause difficulties and distress to parents

The majority of the parents felt that deficits in their child's social and communication skills, lack of self-help skills, and sleeplessness caused most difficulties (based on 100 responses) (Table 67).

**Table 67: Parents view of child behaviours that cause distress or difficulties.**

Types of behaviours	n=100	%
Lack of interaction and play with others	94	94%
Deficits in social skills	93	93%
Language and communication deficits	92	92%
Behaviours that challenge	90	90%
Deficits in self help skills	88	88%
Erratic sleep patterns	80	80%
Excessive ritualistic behaviour	60	60%
Lack of interaction with parents	60	60%
Routine behaviour	49	49%
Weight control	36	36%
Attention deficit and hyperactivity	22	22%
Sexual behaviour	21	21%
Other*	19	19%

\*Includes aggression, diet restriction, epilepsy, no sense of danger, Obsessive Compulsive Disorders (OCD), depression, low self-esteem, hyperactivity, sensory disabilities, and toilet training.

The majority of the professionals felt that parents would have most difficulties with their children's sleep patterns and challenging behaviours, although most felt that social and communication deficits would also cause distress to parents (based on 67 responses) (Table 68).

**Table 68: Professionals view of child behaviours that cause distress or difficulties.**

Types of Behaviours	n=67	%
Erratic sleep patterns	61	91%
Behaviours that challenge	61	91%
Lack of interaction and play with others	58	86%
Language and communication deficits	56	83%
Excessive ritualistic behaviour	54	80%
Deficits in social skills	53	79%
Lack of interaction with parents	52	77%
Routine behaviour	51	76%
Attention deficit and hyperactivity	44	66%
Deficits in self help skills	43	64%
Sexual behaviour	32	48%
Weight control	27	40%
Other *	7	10%

\*Includes aggression, diet, opposition and defiance, obsessions and compulsions, and toileting.

**Key Points:** Child behaviours that cause difficulties and distress to parents.

- Nearly all parents stated that child's lack of interaction and play, deficits in social skills, language and communication deficits, challenging behaviour, and erratic sleep patterns were most emotionally distressing or difficult behaviour experienced; most of the professionals agreed.

**11.14 Siblings**

81 (85%) of the families had more than one child, 57 N.I. and 24 in R.O.I.. The average number of children in these families was 3; the mean age of the child on the autism spectrum was 8 years, the mean age of their siblings was 10 years. Most of the parents thought that their other children experienced feelings of being neglected (80%) or resentment towards the child on the autism spectrum (53%), were worried and anxious about their sibling's condition (67%), or felt they were being treated unfairly (67%). On the other hand, many of the parents thought that their other children were very sensitive to the needs of their sibling on the autism spectrum (65%) and/or to the needs of others (58%) and were actively engaged with their sibling on the autism spectrum (73%) (Table 69).

**Table 69: Parental views of feelings of siblings.**

Sibling feels	n	Agree*	Agree	Neutral	Disagree	Disagree*
Neglected	72	22 (31%)	35 (49%)	3 (4%)	9 (12%)	3 (4%)
Worried	71	20 (28%)	28 (39%)	12 (17%)	8 (12%)	3 (4%)
Resentment	70	7 (10%)	30 (43%)	10 (14%)	15 (22%)	8 (11%)
Guilt or fear	69	1 (1%)	9 (13%)	14 (20%)	23 (34%)	22 (32%)
Treated unfairly	71	13 (19%)	34 (48%)	8 (11%)	8 (11%)	8 (11%)
Isolation from peers	71	3 (4%)	20 (28%)	18 (25%)	21 (30%)	9 (13%)
Willing to help	71	2 (3%)	15 (21%)	23 (32%)	26 (37%)	5 (7%)
Sensitive to sibling	72	15 (21%)	32 (44%)	16 (22%)	8 (11%)	1 (2%)
Sensitive to others	69	12 (17%)	28 (41%)	21 (31%)	5 (7%)	3 (4%)
Engaged	71	19 (27%)	33 (46%)	14 (20%)	4 (6%)	1 (1%)

\*Agree completely; Disagree completely.

Most of the professionals thought that siblings of children on the autism spectrum experienced feelings of being neglected (73%) or resentment towards the child on the autism spectrum (66%), were worried and anxious about their sibling's condition (72%), or felt they were being treated unfairly (67%). On the other hand, many of the professionals thought that siblings were very sensitive to the needs of their sibling on the autism spectrum (71%) and/or to the needs of others (58%) and were actively engaged with their sibling on the autism spectrum (64%) (Table 70).

**Table 70: Professionals view of feelings of siblings.**

Sibling feels	n	Agree*	Agree	Neutral	Disagree	Disagree*
Neglected	64	18 (28%)	29 (45%)	16 (25%)	1 (2%)	-
Worried	58	14 (24%)	28 (48%)	15 (26%)	1 (2%)	-
Resentment	60	17 (28%)	23 (38%)	15 (25%)	4 (7%)	1 (2%)
Guilt or fear	55	9 (16%)	9 (16%)	23 (42%)	11 (20%)	3 (6%)
Treated unfairly	60	15 (25%)	25 (42%)	17 (28%)	3 (5%)	-
Isolation from peers	59	13 (22%)	13 (22%)	24 (41%)	8 (13%)	1 (2%)
Willing to Help	55	11 (20%)	13 (24%)	28 (51%)	3 (5%)	-
Sensitive to sibling	62	14 (23%)	30 (48%)	15 (24%)	3 (5%)	-
Sensitive to others	55	11 (20%)	21 (38%)	21 (38%)	2 (4%)	-
Engaged	59	13 (22%)	25 (42%)	17 (29%)	3 (5%)	1 (2%)

\*Agree completely; Disagree completely.

### Key Points: Siblings.

- 80% of the parents and 73% of the professionals thought that siblings experienced feelings of being neglected.
- 67% of the parents and 72% of the professionals thought that siblings were worried and anxious about their brother or sister with ASD.
- 53% of the parents and 66% of the professionals thought that siblings experienced feelings of resentment towards their brother or sister with ASD.
- 67% of the parents and 67% of the professionals thought that siblings experienced feelings of being treated unfairly.
- 32% of the parents and 44% of the professionals thought that siblings experienced feelings of isolation from their peers.
- 65% of the parents and 71% of the professionals thought that other siblings were very sensitive to the needs of their brother or sister with ASD and/or others.

### 11.15 Impact of ASD on parents and family

Most parents felt that their educational interests (78%), their occupational and employment interests (84%), their personal ability to peruse their social and community interests (86%), as well as their personal ability to peruse their recreational and leisure interests (85%) were restricted by having a child with ASD (Table 71).

**Table 71: Parental view of impact of ASD on personal planning and activities.**

Restricted activity	Agree*	Agree	Neutral	Disagree	Disagree*
Education	38 (41%)	34 (37%)	12 (13%)	8 (9%)	-
Occupation and employment	47 (51%)	30 (33%)	9 (10%)	5 (6%)	1 (1%)
Social and community	52 (55%)	29 (31%)	5 (5%)	7 (8%)	1 (1%)
Recreational and leisure	52 (55%)	28 (30%)	7 (7%)	7 (7%)	1 (1%)

\*Agree completely; Disagree completely.

80 parents had been employed full-time in the past, 56 from N.I. and 24 from R.O.I., but 73 stated that their commitment and their partner's commitment to their child affected their availability for full-time employment, 55 from N.I. and 18 R.O.I..

Most professionals felt that parent's education (78%) and/or occupational and employment interests (84%), parent's personal ability to peruse their social and community interests (94%), as well as parent's ability to peruse their recreational and leisure interests (95%) were restricted by having a child with ASD (Table 72).

**Table 72: Professional view of impact of ASD on parental activities.**

Restricted activity	Agree*	Agree	Neutral	Disagree	Disagree*
Education	25 (40%)	23 (37%)	10 (16%)	4 (6%)	1 (1%)
Occupation and employment	29 (46%)	21 (33%)	9 (14%)	3 (5%)	1 (2%)
Social and community	33 (53%)	26 (41%)	2 (3%)	2 (3%)	-
Recreation and leisure	37 (56%)	25 (39%)	2 (3%)	1 (1%)	1 (1%)

\*Agree completely; Disagree completely.

Most parents felt that having a child on the autism spectrum restricted their family's ability to plan and pursue recreational and leisure interests (82%), social and community interests (86%), and/or go on holidays or family excursions (81%) (Table 73).

**Table 73: Parents view of impact of ASD on family activities.**

Restricted activity	Agree*	Agree	Neutral	Disagree	Disagree*
Recreation and leisure	46 (50%)	30 (32%)	6 (7%)	9 (10%)	1 (1%)
Social and Community	50 (54%)	30 (32%)	5 (5%)	6 (6%)	2 (3%)
Holidays and excursions	40 (51%)	28 (30%)	10 (11%)	7 (7%)	1 (1%)

\*Agree completely; Disagree completely.

Most professionals thought that having a child on the autism spectrum restricted the family in planning and pursuing recreational and leisure interests (97%), social and community interests (95%), and a family's ability to go on holidays or family excursions (98%) (Table 74).

**Table 74: Professional view of impact of ASD on family activities.**

Restricted activity	Agree*	Agree	Neutral	Disagree	Disagree*
Recreation and leisure	38 (58%)	26 (39%)	2 (3%)	-	-
Social and Community	33 (52%)	27 (43%)	3 (5%)	-	-
Holidays and excursions	36 (55%)	28 (43%)	1 (1%)	1 (1%)	-

\*Agree completely; Disagree completely.

Most parents thought that having a child on the autism spectrum restricted their time spent with their partner (78%), their other children (73%), and/or their extended family and friends (76%) (Table 75).



**Table 75: Parental view of impact of ASD on personal social life.**

Restriction on time with	Agree*	Agree	Neutral	Disagree	Disagree*
Partner	41 (46%)	28 (32%)	9 (11%)	9 (11%)	-
Other children	34 (42%)	25 (31%)	13 (16%)	9 (11%)	-
Extended family and friends	48 (51%)	24 (25%)	13 (14%)	9 (10%)	-

\*Agree completely; Disagree completely.

Most professionals thought that having a child on the autism spectrum restricted parents' time spent with their partner (96%), their other children (98%), and/or their extended family and friends (94%) (Table 76).

**Table 76: Professional view of impact of ASD on parents' social life.**

Restriction on time with	Agree*	Agree	Neutral	Disagree	Disagree*
Partner	42 (63%)	22 (33%)	3 (4%)	-	-
Other children	43 (64%)	23 (34%)	1 (2%)	-	-
Extended family and friends	41 (61%)	22 (33%)	3 (4%)	-	1 (2%)

\*Agree completely; Disagree completely.

The following quotations were obtained during the focus group and reflect the views and of the parents regarding impact of ASD on the family and themselves.

*"I always considered myself very good with children with special needs and now I have a child like this. I hope I am able to cope with anything put in my way."*

*"Positive, I think it brought siblings closer together."*

*"Marriage break-up, teacher career put on hold (financial problems). In terms of family life, siblings resent the needs of child with autism on a daily basis."*

*"Had to stay away from friends and family who are very negative towards my autistic daughter, less likely for us to visit friend's house."*

*"The strain it puts on siblings and the guilt you feel on a daily basis that you could be doing more."*

*"Very very stressful. The family seems to disappear. You tend to become isolated and wonder what you ever did to deserve this."*

*"Can't visit my parents when his cousins are there as there is inevitably conflict."*

*"Had to leave my job because of uninformed, unsympathetic colleagues and employer."*

*"Learning to be tolerant, and although we don't like our daughters behaviour we have learned to love her despite this."*

*"Whole family life evolves around the child, both parents unable to work, feel that friends and family don't understand the devastation and worry that we have."*

*“Child’s condition has affected working relations with colleagues, they have no understanding.”*

*“Limited sympathy from employers.”*

**Key Points:** The impact of ASD on parents and family.

- 78% of the parents and professionals agreed that child’s condition restricted parents’ personal ability to pursue their educational interests.
- 84% of the parents and professionals agreed that child’s condition restricted parents’ personal ability to pursue occupational and employment interests.
- 84% parents had been employed full-time in the past; availability for full-time employment was affected by ASD in 77% of the parents.
- 86% of the parents were restricted in pursuing their social and community interests; 94% of the professionals agreed.
- 85% of the parents were restricted in pursuing their recreational and leisure interests; 95% of the professionals agreed.
  
- 82% of the parents felt that their family’s recreational and leisure interests were restricted; 97% of the professionals agreed.
- 86% of the parents felt that their family’s social and community interests were restricted; 95% of the professionals agreed.
- 81% of the parents felt that their family’s ability to pursue holidays or family excursions was restricted; 98% of the professionals agreed.
  
- 78% of the parents felt restricted in the amount of quality time they get to spend with their partner; 96% of the professionals agreed.
- 73% of the parents felt restricted the amount of quality time they get to spend with their other children; 98% of the professionals agreed.
- 76% (72) of the parents felt restricted the amount of quality time they get to spend with their extended family and friends; 94% of the professionals agreed.

### 11.16 Application of ABA to areas other than ASD

Parents felt that ABA was applicable to a wide range of areas other than ASD and in most cases requested further information (Table 77).

**Table 77: Parental view of application of ABA to areas other than ASD and request for further information.**

	ABA applicable	Request information
Area of application of ABA	n	n
Social skills	64 (67%)	60 (63%)
Learning disabilities	56 (69%)	54 (57%)
School education	57 (60%)	53 (56%)
Parenting skills	56 (59%)	54 (57%)
Conduct disorders	49 (52%)	49 (52%)
Sleep problems	45 (47%)	52 (55%)
Self control	42 (44%)	49 (52%)
Aggression Replacement Treatment	33 (35%)	41 (43%)
Stress	32 (34%)	55 (58%)
Attention Deficit Hyperactivity	31 (33%)	34 (36%)
Obsessional Compulsive Disorder	30 (32%)	35 (37%)
Anxiety/phobias	28 (30%)	48 (50%)
Anti-social behaviour	26 (27%)	29 (31%)
Mental Health	25 (26%)	40 (42%)
Sexual Behaviours	23 (24%)	35 (37%)
Weight Control	20 (21%)	37 (39%)
Addictions	15 (16%)	21 (22%)
Paediatrics	14 (15%)	21 (22%)
Marital Therapy	12 (13%)	24 (25%)
Bereavement	12 (13%)	26 (27%)

Professionals felt that ABA was applicable to a wide range of areas other than ASD and in some cases requested further information (Table 78).

Less than a quarter of the professionals considered the application of ABA in the use of single-case designs (Johnston & Pennypacker, 1993) and less than one quarter of the professionals thought more information would be beneficial in any of the areas.

**Table 78: Professional view of application of ABA to areas other than ASD and request for further information.**

	ABA applicable	Request information
Area of application of ABA	n	n
Challenging behaviour	37 (55%)	14 (21%)
Learning disabilities	35 (52%)	14 (21%)
Social skills	35 (52%)	11 (16%)
Attention Deficit Hyperactivity	32 (48%)	17 (25%)
Conduct disorders	25 (76%)	15 (22%)
Anti-social behaviour	25 (37%)	11 (16%)
School education	24 (36%)	9 (13%)
Parenting skills	23 (34%)	13 (19%)
Sleep problems	19 (28%)	9 (13%)
Single-case designs	16 (24%)	6 (9%)
Mental health	14 (21%)	10 (15%)
Obsessional Compulsive Disorder	19 (28%)	8 (12%)
Weight control	17 (25%)	5 (7%)
Self control	17 (25%)	5 (7%)
Aggression Replacement Treatment	16 (24%)	9 (13%)
Anxiety/phobias	15 (22%)	11 (16%)
Stress	15 (22%)	9 (13%)
Sexual behaviours	14 (21%)	10 (15%)
Addictions	9 (13%)	8 (12%)
Bereavement	6 (9%)	4 (6%)
Paediatrics	5 (7%)	6 (9%)

### 11.17 Psychological well being of the parents

88% of the parents perceived their own levels of stress as highly stressed or quite stressed; parents in N.I. appeared more highly stressed than parents in R.O.I. (Table 79).

**Table 79: Parental perception of personal stress level.**

	Highly stressed	Quite stressed	Not stress at all
n=94	n	n	n
N.I.	26 (38%)	34 (49%)	9 (13%)
R.O.I.	5 (20%)	18 (72%)	2 (8%)
Total	31 (33%)	52 (55%)	11 (12%)

High levels of stress had been continuous for an average of 55 months (SD=31.0). 94% of the parents who reported feeling quite stressed stated that this had been the case for an average of 64 months (SD= 38.4).

In terms of general psychological health as measured by the General Health Questionnaire (GHQ-12), parents scored an average of 4.35 (SD=3.99), within a range of 0-12 points. Validity of GHQ-12 was supported through Pearson correlation analysis that identified medium/high correlation of personal assessment of perceived stress levels with GHQ-12 scores (n=94;  $r=-.41$ ;  $p<.01$ ).

GHQ-12 scores were not statistically significant with regard to the child's age, diagnostic process, dual diagnoses, siblings with a diagnosis, employment, demographic location, home tuition, education, home, family, or respite support.

Pearson correlation analysis indicated a positive relationship between number of MDT supports and GHQ-12 scores, i.e. higher number of MDT supports was associated with higher GHQ scores (n=95;  $r=.28$ ;  $p<.01$ ).

However, as expected, independent samples t-test showed that those who receive family support had lower GHQ-12 scores than those who did not ( $t=-2.06$ ;  $df=90$ ;  $p<.05$ ) (Table 80).

**Table 80: GHQ-12 mean scores and family support.**

Family support	n	Means	SD
Family support received	59	3.85	3.72
No family support	33	5.61	4.27

48% of the parents scored on or above a threshold 4 indicating 'caseness' in need of further psychological assessment (Table 81).

**Table 81: GHQ-12 threshold of 'caseness'.**

	GHQ Score <4	GHQ Score ≥4
	n	n
N.I.	34 (49%)	35 (51%)
R.O.I.	15 (58%)	11 (42%)
Total	49 (52%)	46 (48%)

Of the parents who scored on or above the GHQ-12 threshold (n=46),

- 83% (n=38) had a child with dual diagnoses, 29 from N.I. and 9 from R.O.I..
- 85% (n=39) had children aged 12 years and under, 28 from N.I. and 11 from R.O.I..
- 59% (n=27) have considered moving their family in order to avail of more appropriate education provisions for their child, 19 from N.I. and 8 from R.O.I..
- 82% (n=37) were in receipt of MDTs, 29 from N.I. and 8 from R.O.I..
- 73% (n=33) were not receiving home and family supports, 28 from N.I. and 5 from R.O.I..
- 71% (n=32) were not receiving respite support, 22 from N.I. and 10 from R.O.I..

**Key Points:** Psychological well-being among parents.

- 33% of the parents were highly stressed, 26 from N.I. and 5 from R.O.I., for an average duration of 55 months.
- 55% of the parents were quite stressed, 34 from N.I. and 18 from R.O.I., for an

- average duration of 64 months.
- GHQ-12 scores were highly correlated with perceived stress levels.
- 48% of the parents scored on or above the threshold for psychiatric case identification, 35 from N.I. and 11 from R.O.I.. Of these parents, 83% had a child with dual diagnoses; 85% had children aged 12 years and under; 73% were not receiving home or family support; 71% were not receiving respite support.
- Parents who received MDTs scored significantly lower on the GHQ-12.
- Parents who received support from their family scored significantly lower on the GHQ-12.

### 11.18 Future needs

99% of the parents and professionals either agreed completely or agreed that increase support and guidance during the diagnosis process should be in place for families of children with ASD in the future (Table 82).

**Table 82: Future need for support and guidance during the diagnosis process.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	87 (92%)	7 (7%)	1 (1%)	-	-
Professionals	67	59 (88%)	7 (11%)	1 (1%)	-	-

\*Agree completely; Disagree completely.

98% of the parents and 100% of the professionals either agreed completely or agreed that increased MDTs should be in place for families of children with ASD in the future (Table 83).

**Table 83: Future need for increased provisions of multi-disciplinary therapies.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	82 (86%)	11 (12%)	2 (2%)	-	-
Professionals	67	57 (86%)	9 (14%)	-	-	-

\*Agree completely; Disagree completely.

93% of the parents and 97% of the professionals either agreed completely or agreed that increased home and respite support should be in place for families of children with ASD in the future (Table 84).

**Table 84: Future need for increased home and respite supports.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	94	75 (80%)	12 (13%)	5 (5%)	-	-
Professionals	66	55 (83%)	9 (14%)	1 (1.5%)	-	1 (1.5%)

\*Agree completely; Disagree completely.

98% of the parents and 95% of the professionals either agreed completely or agreed that increased opportunities should exist for children with ASD to participate in community and social activities in the future in (Table 85).

**Table 85: Future need for opportunities for children with ASD to participate in community and social activities.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	82 (86%)	11 (12%)	2 (2%)	-	-
Professionals	64	50 (78%)	11 (17%)	1 (2%)	2 (3%)	-

\*Agree completely; Disagree completely.

97% of the parents and 73% of the professionals either agreed completely or agreed that a family advocate should be appointed for families of children with ASD in the future (Table 86).

**Table 86: Future need for the appointment of a family advocate.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	91	68 (75%)	11 (12%)	12 (13%)	-	-
Professionals	62	26 (42%)	19 (31%)	16 (26%)	-	1 (1%)

\*Agree completely; Disagree completely.

98% of the parents and 92% of the professionals either agreed completely or agreed that increased opportunities for parental involvement in the creation and review of care plans should be in place for families of children with ASD in the future (Table 87).

**Table 87: Future need for increase parental involvement in the creation and review of care plans.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	94	80 (85%)	12 (13%)	2 (2%)	-	-
Professionals	64	43 (67%)	16 (25%)	4 (6%)	1 (2%)	-

\*Agree completely; Disagree completely.

All of the parents and 97% of the professionals either agreed completely or agreed with the need for structured and comprehensive care plans to address future needs of children with ASD (Table 88).

**Table 88: Future need for care plans to address a child's future needs.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	83 (87%)	12 (13%)	-	-	-
Professionals	66	49 (74%)	15 (23%)	1 (1.5%)	1 (1.5%)	-

\*Agree completely; Disagree completely.

All of the parents and 98% of the professionals either agreed completely or agreed that greater sharing of information between professionals should be in place in the future for families of children with ASD (Table 89).

**Table 89: Future need for greater sharing of information between professionals.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	94	85 (90%)	9 (10%)	-	-	-
Professionals	63	47 (74%)	15 (24%)	1 (2%)	-	-

\*Agree completely; Disagree completely.

99% of the parents and 57% of the professionals either agreed completely or agreed that increased opportunities for ABA-specific schooling should be in place in the future for families of children with ASD (Table 90).

**Table 90: Future need for increased opportunities for ABA\*\* schooling.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	86 (91%)	8 (8%)	-	1 (1%)	-
Professionals	64	28 (44%)	8 (13%)	20 (31%)	6 (9%)	2 (3%)

\*Agree completely; Disagree completely.

\*\*Training and teaching to be provided by a qualified Behaviour Analyst – trained to BCBA/PhD level.

99% of the parents and 68% of the professionals either agreed completely or agreed that increased opportunities for general ABA training should be in place in the future for families of children with ASD (Table 91).

**Table 91: Future need for opportunities for general parent training in ABA\*\*.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	95	81 (85%)	14 (15%)	-	-	-
Professionals	64	29 (45%)	15 (23%)	19 (30%)	1 (2%)	-

\*Agree completely; Disagree completely.

\*\*Provided by a qualified Behaviour Analyst – trained to BCBA/PhD level.

94% of the parents and 57% of the professionals either agreed completely or agreed that increased opportunities for general siblings training in ABA should be in place in the future (Table 92).

**Table 92: Future need for opportunities for general sibling training in ABA\*\*.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	94	66 (70%)	22 (24%)	5 (5%)	1 (1%)	-
Professionals	64	22 (34%)	15 (23%)	21 (33%)	5 (8%)	1 (2%)

\*Agree completely; Disagree completely.

\*\*Provided by a qualified Behaviour Analyst – trained to BCBA/PhD level.

98% of the parents and 95% of the professionals either agreed completely or agreed that increased opportunities for general parent training in ASD should be in place in the future (Table 93).

**Table 93: Future need for opportunities for general parent training in ASD.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	92	72 (78%)	18 (20%)	2 (2%)	-	-
Professionals	65	50 (77%)	12 (18%)	3 (5%)	-	-

\*Agree completely; Disagree completely.

73% of the parents and 86% of the professionals either agreed completely or agreed that increased opportunities for general parent training in TEACCH should be in place in the future (Table 94).



**Table 94: Future need for opportunities for general parents training in TEACCH.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	89	47 (53%)	18 (20%)	17 (19%)	3 (4%)	4 (5%)
Professionals	58	29 (50%)	21 (36%)	8 (14%)	-	-

\*Agree completely; Disagree completely.

All parents and 96% of the professionals either agreed completely or agreed that the families of children with ASD should receive professional advice highlighting services and entitlements available to families (Table 95).

**Table 95: Future need for professional advice on services and entitlements.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	94	85 (90%)	9 (10%)	-	-	-
Professionals	63	47 (74%)	14 (22%)	1 (2%)	1 (2%)	-

\*Agree completely; Disagree completely.

All parents and 95% of the professionals either agreed completely or agreed that the families of children with ASD should received professional advice on financial planning for a child's future (Table 96).

**Table 96: Future need for professional advice on financial planning.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	93	84 (90%)	9 (10%)	-	-	-
Professionals	61	39 (64%)	19 (31%)	1 (2%)	2 (3%)	-

\*Agree completely; Disagree completely.

90% of the parents and 87% of the professionals either agreed completely or agreed that parental choice should be increased with regard to the recruitment and appointment of home support workers in the future (Table 97).

**Table 97: Future need for increased parental choice of home support workers.**

	n	Agree*	Agree	Neutral	Disagree	Disagree*
Parents	93	68 (73%)	16 (17%)	8 (9%)	1 (1%)	-
Professionals	63	37 (59%)	18 (28%)	6 (10%)	2 (3%)	-

\*Agree completely; Disagree completely.

9% (n=9) of the parents required other provisions, included counselling, emergency support, future planning, increased professional awareness of ASD, increased opportunities for ASD teacher training, and ASD assessments. 5% (n=3) of the professionals required other provisions, i.e., increased provisions for speech and language therapy.

The following quotations were obtained during the focus group and reflect the views and of the parents regarding future needs.

Future worry:

*"I worry who is going to look after her when I die. I worried about her deterioration in IQ levels, and I worry how all this affects her brothers' behaviour."*

## ASD: Meeting the needs of families

*“What happens to my child when we are no longer here to look after her?”*

*“There is nowhere to go when they turn 19 years of age.”*

*“Transition into secondary school.”*

*“His mental health.”*

*“Residential and who will take care of him after my days are over.”*

*“Provisions for his care when we get older.”*

### Unmet needs:

*“Waiting times to see therapist, education and social services.”*

*“The provisions of education, speech therapy and occupational therapy.”*

*“Support in learning about your child’s condition.”*

*“Thorough ongoing social skills programmes for all kids.”*

*“Cohesive services offered immediately after diagnosis.”*

*“Help is needed in dealing with teenagers’ depression, low self-esteem and lack of motivation.”*

*“Key worker system is needed.”*

*“Greater general and public awareness.”*

### Education:

*“Need to listen to parents.”*

*“Greater interaction, speech therapy, classroom assistants, should be more readily available with more money put in place for ABA schools.”*

*“Specific school needed catering for these children’s unique needs.”*

*“Secondary education, there is absolutely nothing in place for our kids at secondary level.”*

*“Teachers need to know the signs of ASD and warn the parents.”*

*“Training for teachers and classroom assistants in ABA.”*

*“Appropriately trained professionals to deliver training.”*

## ASD: Meeting the needs of families

*“More support and information on the transition from primary to secondary school.”*

*“More after-school services.”*

*“Adequate schooling with small class sizes and ABA provision.”*

*“Education should continue into adulthood.”*

### Health:

*“Speech therapy, occupational therapy, ABA programmes from trained professionals should be available throughout the health boards.”*

*“Mental health and depression.”*

*“Emotional well being and social skills of children.”*

*“More respite and family support needed.”*

*“An established process and referral route after diagnosis has been obtained.”*

### Parent and professional partnership:

*“Professionals to communicate to me in the same manner and respect as they would interact in their dealings with other professionals.”*

*“Professionals need to be more accommodating. There is always an underlying feeling that it’s them against us. Barriers need to be broken.”*

*“Can [voluntary agencies]...please work together.”*

*“A parent-professional partnership needs to exist first.”*

*“Respect of the parents, we are the parents and should be allowed to make decisions for our child.”*

*“They need to listen to us and take notice.”*

### **Key Points:** Future needs

Nearly 100% of the parents and nearly 100% of the professionals agree that there is future need for:

- support and guidance during the diagnosis process;
- increased provisions of multi-disciplinary therapies;
- increased home and respite supports;
- increased opportunities for children with ASD to participate in community and social activities;
- for the appointment of a family advocate;

- increase parental involvement in the creation and review of care plans;
- for care plans to address a child's future needs;
- greater sharing of information between professionals;
- professional advice on services and entitlements;
- professional advice on financial planning;
- increased parental choice of home support workers

Nearly 100% of the parents and many of professionals agreed that there is future need for:

- increased opportunities for ABA schooling;
- increased opportunities for general parent training in ABA;
- opportunities for general sibling training in ABA;
- opportunities for general parent training in ASD;

86% of the professionals and 73% of the parents agreed that there is future need for general parents training in TEACCH.

## 12. Discussion

In line with recommendations of the *Mental Health and Learning Disability Review* (Bamford & McClelland, 2006), a comprehensive needs assessment of parents of children on the autism spectrum, the children, and professionals working with these families was carried out in order to assess services currently provided, identify the needs of families, and to arrive at recommendations to ensure that a holistic perspective on future support and intervention is tailored to individual child, parent, and family systems. The project aimed to inform future strategic decision making of professionals, policy makers, and researchers. Comparative data were collected in N.I. and the R.O.I.. In total, 95 parents representing 100 children with ASD and 67 multi-disciplinary professionals took part. A mixed-methods approach was used; detailed questionnaires supplied quantitative data and a focus group contributed qualitative data. Results indicate a severe lack of statutory service provision, in particular in N.I.; deficiencies in the actualisation of parent-professional partnerships; prolonged waiting times for diagnosis and 'statementing' processes; and absence of a coherent view on science-based policy and practice. While parents and professions largely agreed about future needs there were some significant discrepancies with regard to the basis of interventions.

### 12.1 Prevalence and diagnosis

A number of issues arose from this research. Lack of accurate prevalence rates and the absence of a central database of families and children with ASD made it impossible to identify the exact size of the target population. To overcome this problem, modern technologies, e.g., emails, webpages, as well as traditional methods, e.g., posters, flyers, word of mouth, were used to disseminate the call for participation. Consequently, the sample used in this research can be considered to largely reflect the views of families of children with ASD and professionals working in this field.

Results showed that the diagnosis of ASD was a difficult process that can take a long time (average 16 month, ranging up to 4+ years), is carried out in a way that many parents find distressing, entails information that many parents find unclear and difficult to understand, and does not lead to clear advice for parents and families on how to proceed after diagnosis. This state of affairs causes not only problems with regard to discovering prevalence rates but has negative effects in terms of treatment decisions and long-term prognosis. Participating professionals realised that parents experience high levels of distress when trying to access quick and efficient diagnosis. Some parents turned to private practitioners and were served much faster (2-3 months) than those depending on publicly funded diagnosticians. Of course, the question is how private diagnosis compares to publicly funded diagnosis in terms of reliability and validity, but the fact remains that individual parents pay large amounts of money to ensure that the process is quick and efficient and that consequently intervention can begin early.

This development is of concern because private diagnosis usually means uni-disciplinary diagnosis while multi-disciplinary diagnostics are generally recommended (Charman & Baird, 2002). It is also discriminatory, because it means that children of parents who cannot afford to pay for private diagnosis are disadvantaged. It is imperative for professionals who ascribe to anti-discriminatory practice and evidence-based practice to find ways to speed up publicly funded diagnostic services. There now exist validated, reliable, and widely used procedures for assessment and diagnosis. For example, the ADOS and the ADI-R (Lord et al., 1997; 2000) are widely used diagnostic tools based on DSM-IV criteria for ASD. These tests include children and parents, use interview and direct observation methods, and take one or two sessions to complete. Multi-disciplinary observations can be conducted through use of two-way mirrors or video recordings (Dawson et al., 2000) so that children do not have to meet too many professionals (Goin-Kochel et al., 2006). Consequently, the duration from initial assessment to formal diagnosis can be reduced to recommended levels, i.e., not to exceed 90 days.

Subsequent to diagnosis, a Special Educational Needs Statement (SENS) should identify educational needs of the child. Again this process takes a very long time (average 10 month, ranging up to 3+ years) and nearly half of the parents stated that the resulting document does not describe their child's individual needs accurately and that provisions outlined in their child's statement are not appropriate to their child's needs. These findings concur with the Report of the Task Group on Autism' (2002) and O'Connor et al. (2006).

There is some uncertainty regarding the exact recommended time frames for 'statementing'. Under the Education (Special Educational Needs) Regulations (N.I.) (2005; Statutory Rule No. 384), Education and Library Boards have to fulfil their obligations within six weeks of a parent (or responsible body) seeking an assessment, while Articles 15(4) or 20A (7) state that when a Board has "given notice to the child's parent of its decision to make an assessment it shall complete that assessment within 10 weeks beginning with the date on which such notice was given" (Special Education Needs Statement, 2007). In any case, findings reported here show general non-adherence to the Education (N.I.) Order (1996) that gives clear guidance on the required code of conduct:

"In normal circumstances, the length of time taken for a Board to reach the stage of issuing a proposed statement must be no more than 18 weeks from the date of either the receipt of the parent's request for an assessment or the issue of the notice under Article 15(1), whichever is appropriate." (Article 3(35), p.31)

Together, then, diagnosis and ‘statementing’ should take no more than 6-7 months. However, most parents reported that the process took at least 2 years (in some cases over 4 years) by which time their children were well over 5 years old. While some generic support services may be available prior to diagnosis, intensive intervention is usually postponed until a diagnosis is available. There is clear scientific evidence, however, that postponement prohibits some of the most important benefits and that early ABA-based intensive intervention is most effective if it starts before the child’s 3<sup>rd</sup> birthday (Smith et al., 2000).

## 12.2 Treatment

Once a child is diagnosed, treatment can begin. However, as far as intervention choices were concerned, a difference was apparent between the two jurisdictions. In N.I. the majority of children were in home tuition programmes, while in R.O.I. most of the children were in ABA-based schools. This difference occurred due to a difference in legislation between the two jurisdictions:

- The Education (N.I.) Order (1996/1998) specifies the statutory duty of education boards to “make arrangements for the provision of suitable education at school or otherwise than at school” and to ensure that the “placement is deemed appropriate to the child’s needs, while also compatible with the interests of other children already in the school, and with the efficient use of the Board’s resources” (para 4.34). Although there no longer is the requirement to name a school in the SENS, “if the child’s parent has made suitable arrangements for the special educational provision specified in the statement to be made for the child” (Statutory Instrument, 2005), funding for educational provision is allocated to schools. Parents who do not consider this educational provision appropriate for their child’s needs generally are not offered alternatives.
- In R.O.I., despite the fact that free primary education is available, the Constitution (Article 42) gives parents the right to have education provided for their child by ‘other means’. By respecting parents as primary and natural educators of their children, Article 42 enables them to select appropriate schooling using funding allocated for their child’s education. In fact, Mr. Justice Barr stated recently that the ultimate criteria for interpreting the State’s constitutional obligation to provide for primary education should be need, not age.

Most of today’s parents of children diagnosed with ASD do an enormous amount of research regarding intervention methods themselves (e.g., using internet, library resources), and share information with other parents, and are well-informed about best practice, evidence- and science-based interventions, and educational opportunities for their children. Consequently, R.O.I. parents were able to decide to send their children to schools where education was based on the best available scientific evidence or even to set up these kinds of schools themselves (Smyth et al., 2005). The difference in legislation has lead to a situation where the number of ABA-based schools rises steadily in R.O.I. (IAA, 2005), while there is not one ABA-based school in N.I., despite the fact that most of the PhD-level ABA professionals who helped parents initially in R.O.I. were trained in N.I. (Keenan et al., 2000; Keenan, 2005). In N.I., only 6 ABA-based education places are offered in a special needs school facilitated by a voluntary agency specially set up for this purpose, i.e., SPEAC. In contrast, the Bureau of Developmental Disabilities Services (2006) stipulated that ABA services should provide “a minimum of 4 to 6 hours of services 5-7 days a week

for a period of 2-3 years”(p.20). In view of the absence of ABA schools, parents in N.I. largely relied on home tuition programmes (home tuition in N.I.:R.O.I. was at a ratio of nearly 8:1). However, home programmes were poorly supported by professionals (only 13% parent learned about home programmes from professionals, only one statutory staff was involved in N.I., only in 4% of cases was there partnership with school) and most home tuition was carried out by parents themselves, many of whom had given up employment to do so.

Over half of the home tuition programmes were supervised of a qualified behaviour analyst (provided by a PhD level trained behaviour analyst who was employed by a charity, PEAT) and the vast majority of home tuition was highly specific to each child’s needs. The difference in uptake of home tuition programmes between the two jurisdictions raises ethical as well as practical concerns, especially for children whose parents are unable to offer appropriate home tuition programmes.

Clearly, parents were prepared to go to great length to obtain appropriate services for their children. For example, they were prepared to move house, to spend their own money, to re-mortgage their homes, and to take statutory services providers to tribunals (Mayerson, 2004). With regard to their children’s education, most N.I. parents were dissatisfied with the education offered by schools. While not all the issues were resolved in R.O.I. either (e.g., ABA-based schools are still considered *Models of Education* rather than being fully integrated into statutory provision) there is a growing awareness that science-based intervention is the way forward and R.O.I. parents seem much more content with their children’s school-based education.

Solity (1991) identified problems with the lack of science-based training in education some time ago when he summarised how behavioural techniques are merely grafted onto classroom management without the full understanding of the psychological principles that underpin these techniques:

“The use of behavioural approaches culminated in the arrival on the educational scene of a number of training packages. ... [that] have invariably been grafted on to existing practice. ... Teachers viewed the approach as something different from everyday practice which was essentially only for those children experiencing difficulties. ... If the curriculum is to be responsive to children's learning, it is important that teachers learn the general principles and concepts on which programmes are based so that they can be revised and amended, as appropriate. Prescribing curricula and checklists in the context of behavioural training packages rarely encourages this. ... On the contrary, they are seen as an immediate panacea and invariably create the impression that there are ready made solutions to problems. When children fail to make the expected progress there is a danger that they will be seen to have failed and will be regarded as having difficulty in learning rather than the training materials becoming the subject of further investigation and subsequent amendment.”(p. 161)

### **12.3 Staff and parent training**

Despite the lack of support for home tuition, early intensive intervention, or ABA schooling, one third of professionals stated that they had studied ABA as part of their undergraduate or postgraduate education. The depth and level of this study was uncertain.

For example, in N.I. there are only a couple of undergraduate ABA modules available at one of the universities, while there are no ABA modules at other universities, where students receive at most a very general lecture about 'behavioural approaches' (cf. Module handbooks University of Ulster, UU; Queen's University of Belfast, QUB; Open University, OU). The first intake of the new Masters in ABA at UU coincided with the beginning of the present study and therefore had not been available to professionals included in this study.

Most of the training referred to by professionals occurred in short courses or conferences. Given the clear guidelines provided by the Behavior Analysis Certification Board as to the required standards of training, short courses or conferences, are not to be considered 'training', but rather examples of Continuous Professional Development (CPD). While local documents and reports seem not to make the distinction between training on short courses and training to international standards (ASD Working Group, 2007; McConkey et al., 2007; Report of Task Force on Autism, 2001; Report of Task Group on Autism, 2002), recent international reports acknowledged training standards set by BACB and required that

"ABA providers be certified by the BACB. It was expected that high demand for ABA services would provide incentive for large numbers of ABA providers to become certified BCBAs and BCABAs." (Department of Defence, 2007, p. 11)

The level of training required in order to be permitted to deliver applied behaviour analysis services is clearly outlined in the Bureau of Developmental Disabilities Services (2006) service definitions and standards.

Nearly all of the professional participants acknowledged that they required further ABA training and the challenge is to develop appropriate courses. Indeed, professionals were much less knowledgeable than parents about the wide range of applications of ABA. More worryingly, though, they seemed to be much less interested in receiving information. This finding reflects a substantial problem in much of the autism literature (Humphrey & Parkinson, 2006), which leads many professionals to view ABA as only one specific treatment for autism. As mentioned earlier, Chiesa (2005) outlined clearly that none of the 'A's in ABA stand for autism. Making the distinction between the application of the science of behaviour analysis (ABA) for children with ASD and commercially branded autism-specific treatment packages (see Figures 2 & 3) is important especially when specific technologies that are based on the science become available on the shop floor. This can be very confusing for the consumer (i.e., the parent) and the onus is on professionals to get it right.

"it had become apparent ... that the autism world continued to be dominated by an astonishing amount of misinformation, false expertise, and ferocious ideological warfare. It is equally apparent, given the growing research findings about the value of early intervention, that there was a critical need for parents to gain access to science-based accurate information about such interventions." (Maurice et al., 1996, p. 8)

Getting this right is particularly important also because, as mentioned earlier, despite the fact that local reports did not include ABA professionals as members of their working groups and despite repeated requests to remedy this situation, these reports are used to make policy decisions. Not surprisingly, mistakes were made repeatedly in these reports



with regards to ABA; e.g., ABA was described as a “highly formalised method of 1:1 instruction ... frequent, repetitive drills” (Report of Task Force on Autism, 2001) or the “Lovaas approach” (Report of the Task Group on Autism (2002), and more recently, a report commissioned by the Department of Education in N.I. asserted that in intervention studies ABA treatment was not “compared to another form of intervention” (McConkey et al., 2007, p. 23). These ideas stand in stark contrast the actual and historically well-established definition of ABA mentioned earlier (Baer et al., 1968; Cooper et al., 2007) and international findings from comparative studies (e.g., Howard et al., 2005). For example in Canada, a thorough review of the literature found that

“ABA is an approach that includes a large variety of specific methods of assessment and intervention which are based on objective, empirical evidence, and which may be applied to individuals with a wide variety of diagnoses (or no diagnosis). It is not necessarily restricted to Autism or to young children, does not necessarily involve one-to-one teaching, and is not necessarily intensive.” (Perry & Condillac, 2003, p. 69)

While parents who participated in the research reported here were unanimous about the need for ABA for their children, participating professionals confirmed that statutory bodies were not encouraging or prepared, i.e., “when parents seek support for such a service the boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect.” (Report of Task Group on Autism, 2002, p. 37).

In fact, five years after the Task group admitted shortcomings with regard to science-based service provisions, statutory bodies still rely on parents and voluntary bodies to provide these services, as a recent draft report by the Northern Health and Social Service Board on a strategy for ASD (ASD Working Group, 2007) confirmed:

“Trusts do not provide specific training in ASD awareness; ... Parents can ... receive training from local voluntary groups ... focused on providing training and advice on ABA, i.e., PEAT, CEAT (Centre for Early Autism Treatment), and SPEAC (Special Provision for the Education of Autistic Children).” (p. 35)

Effective science-based intervention in N.I., then, remains the responsibility of parents and voluntary bodies and is carried out mainly by parents in their own homes, rather than being embraced by statutory agencies.

In addition, parents were not informed about availability of financial support and the actual amounts N.I. parents received compared unfavorably to financial support received by parents in R.O.I.. It has been said that ABA home tuition is expensive and time consuming, however, the amounts of money available to parents were minimal and lack of adequate resources affected the intensity of programmes negatively. Thus, if appropriate interventions were offered by educational services, parents would not have to depend on financial assistance or leave work to ensure that their children receive appropriate education. This would make financial sense, as most SEN schools presently have a teacher:student ratio of 1:1 or 1:2 and therefore the question is not ratio or finance but the training of these teachers in science-based methods of intervention. A recent report on the economic consequences of autism in the UK identified extremely high costs associated with supporting children and adults with ASD that

“warrant attention because there ought, potentially, to be some scope for reducing them by making more widely available those early interventions that have been shown to alter patterns of behaviour. Those interventions could divert many people from care pathways that are expensive, as this report shows, and improve the quality of life of those individuals and their families. (Knapp et al., 2007, p.23)

#### **12.4 Parent-professional partnership**

While most of the children had educational plans and these were reviewed regularly, many parents felt that these plans were only sometimes appropriate and that parental views were not included sufficiently. It seems, therefore, that while lip service may be paid to parental participation and partnership schemes (e.g., Department of Education, 2007), ultimately parents' views were not given appropriate weight when it comes to children's education, especially if these views differ from those held by professionals in statutory establishments. This is an important point not only because of equality issues. It is most important because parents who undertake parent training and subsequently implement detailed and scientifically-based home tuition programmes that are scrupulously monitored can become more knowledgeable than professionals about scientifically validated interventions. Many of the parents reported that detailed data regarding their children's behavioural changes in home tuition programmes were not included consistently in the educational plans of their children, despite the acknowledged need for improvements (O'Connor et al., 2006). One of the reasons for non-inclusion of intervention data may be found in the general perception that autism as a life-long condition and improvements are developmental rather than learned or treatment dependent.

“With the exception of a very few high-functioning individuals, our students' difficulties ... will be a lifelong handicap” (Watson et al., 1989, p.6).

The debate about the distinction between learning and development has a long history (Baer, 1970; 1973). In this context it is important to note that children diagnosed correctly with ASD have been re-diagnosed after successful treatment and this possibility should be considered in reviews of plans.

There was a large discrepancy between multi-disciplinary support and therapy (MDT) presently in place and MDT future requirements; an average of 3 professionals were available for each child, while future requirements include an average of 9 professionals, such as a speech and language therapist, occupational therapist, clinical psychologist, educational psychologist, behaviour analyst, special education needs teachers, autism therapist, social worker, and a paediatrician.

The finding of a strong correlation between number of MDT and high GH-12 scores was intriguing. There is no doubt that the expertise from MDT professionals is invaluable, yet parents who received more MDT support were more stressed than parents who received fewer MDT supports. While it is possible that parents who were more stressed sought out more MDT supports, it is also possible that the diversity of MDT supports caused additional stress and that the key issue is the question of consistency and coherence of multi-disciplinary support. We now know that eclectic approaches are not as effective as science-based behaviour analytic interventions (Howard et al., 2005; Zachor, et al., 2007). Therefore it would make sense if all MDT professionals were trained in the science of behaviour and able to apply this science to their own area of expertise, as is the case for

example in the New England Centre for Children, Boston, USA (2007) and the Morningside Academy, Seattle, USA (2007).

Parents and professional agreed that there were times when families require home, family, or respite services and that by and large these services were not available sufficiently. However, it is not only availability of services that was the issue here. Similar to the importance of a coherent approach by the multi-disciplinary team, it is important that home, family, or respite support workers carry out interventions consistently. In other words, staff involved in home, family, and respite support need to be trained to use a coherent scientific approach.

This is imperative as parents and professionals largely agreed about the actual child behaviours that cause concern; such as lack of interaction and play with others, deficits in social skills, language and communication deficits, challenging behaviour, and erratic sleep patterns. A consistent approach to these behaviours across settings (e.g., home, school, respite) would make sense.

Parents and professional also agreed on the impact of having a sibling diagnosed with ASD. Siblings were thought to experience feelings of being neglected and treated unfairly and isolated from their peers. With regard to their sibling with ASD, parents and professionals agreed that brother and sisters felt worry, anxiety, and general sensitivity, but also at times, resentment. Support and inclusion of siblings is important and parents were clear about the need for sibling training in ASD and ABA.

The personal impact of having a child with ASD on parents themselves was considerable. On the whole, parents and professionals agreed that the child's condition restricted parents' personal ability to pursue their education, occupation, and employment, e.g., many of the parents had left work to look after their child. Although it is considerable, it is difficult to estimate the impact this had on the general economy (cf. Knapp et al., 2007), however, the impact on the economic welfare of a family was obvious. With rising costs of living, most families to-day depend on two wage earners and low income families are at risk of falling into a poverty trap, especially if there are additional costs associated with a child requiring interventions not offered by statutory agencies. Appropriate schooling for the children with ASD would allow parents to return to paid employment, while feeling content with their children's day provision.

Most of the parents also reported not being able to pursue social, recreational, or leisure interests, such as family excursions, time with their partners, their other children, or friends. These limitations were recognised by professionals and stress levels were high amongst these parents. According to GHQ-12 scores the general mental health of early half of these parents (48%) caused concern and should be assessed in more detail. This figure compares to 17% in the general population in N.I. (Northern Ireland Life and Times Survey, 2006). Parental stress was related significantly to social and professional support levels.

This is an interesting point when considered in conjunction with treatment choices. While all of the parents identified a need for more school- and family-based ABA training and provision, quite a few of the professionals thought this should be TEACCH-based. In the past, this would have seemed logical because in the absence of an alternative, the TEACCH package was the dominant approach used with children with ASD. However, for

some enigmatic reason it remains widely supported within the professional community in N.I. (cf. McConkey, et al., 2007; Report on Task Group on Autism, 2002), seemingly undeterred by the lack of rigorous scientific evidence of effectiveness (Fletcher-Campbell, 2003; Ozonoff & Cathcart, 1998; Parr, 2007) and irrespective of the fact that the developers of the TEACCH package themselves suggested the use of aversives.

“Schopler, et al. (1980), describe the use of "aversive and painful procedures" such as meal deprivation (p.121), "slaps or spansks on the child's bottom" (p.121), or "electric shock, unpleasant tasting or smelling substances" (p.122) as appropriate interventions if positive methods are ineffective” (quoted in Sallows, 2000, p. 48).

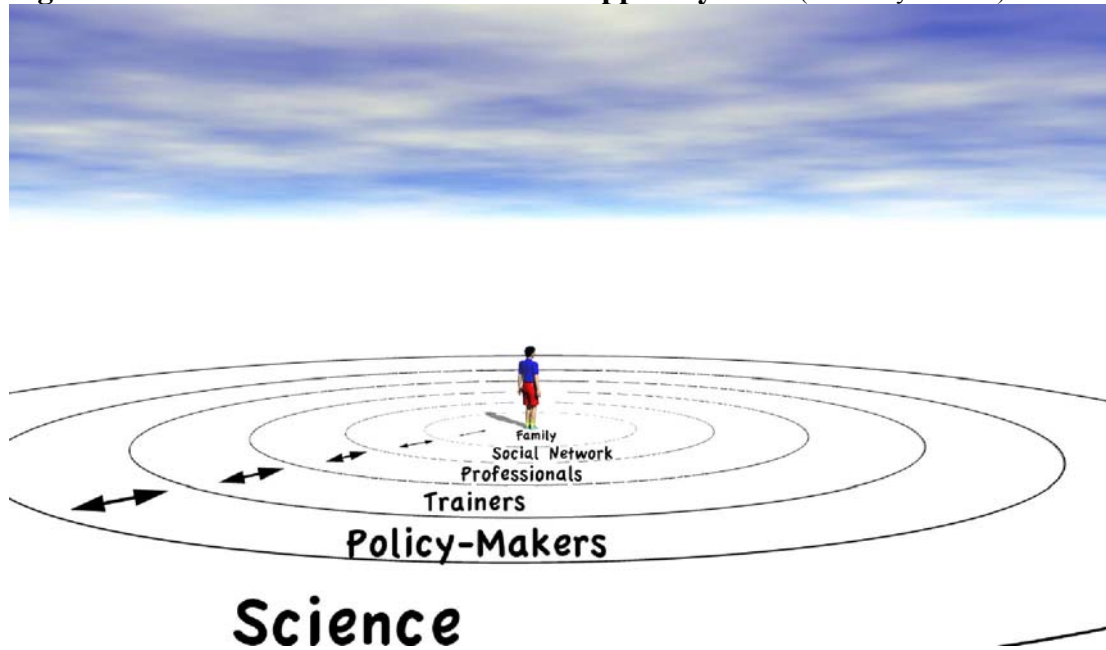
Further problems arise from the TEACCH philosophy, that views people with ASD as necessarily requiring lifelong care. As such the programme does not aim to achieve integration of people with ASD into mainstream society, but to provide a “prosthetic environment” (Jordan et al., 1998, p.79) across the lifespan, in which autism is accommodated and problem behaviours avoided by offering “a continuity of services from preschool to adult life” (Jordan et al., 1998, p.79). In contrast, parents consistently preferred to rely on the practices of a science, backed by a large body of research (Larsson, 2005), that views ASD as a descriptive summary label for a range of behaviours, that changes as behaviour changes, and that does not endorse the use of aversives (Sallows & Graupner, 2005). Johann Wolfgang Goethe’s (1749-1832) captured the difference when he wrote, “If I accept you as you are, I will make you worse; however if I treat you as though you are what you are capable of becoming, I help you become that.”

As mentioned earlier, ABA was introduced to Ireland through a parent-led charity in 1997 (PEAT, 2007). By now there are some other voluntary and private agencies (namely, CEAT and SPEAC) that offer ABA-based services in N.I.. Parents who want to avail of ABA for their child largely have to rely on parent-led initiatives or pay business rates, have to fight for help, and even have been criticised for being ‘vocal’ in their demand for science-based intervention to be provided by education boards (McConkey et al., 2007, p.37). However, the voice of these parents is in accord with international views held by many professionals and academics (e.g., Perry & Condillac, 2003; Appendix 5). Indeed, the following statement appears in the official journal of the American Academy of Pediatrics:

“The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings.” (Myers & Johnson, 2007, p.1164)

Together, then, findings reported here support the model of a systemic approach based on science that forms the foundation of holistic, child- and family-centered services delivery (Figure 7).

**Figure 7: Model of science-based holistic support systems** (©Mickey Keenan).



### 13. Conclusion

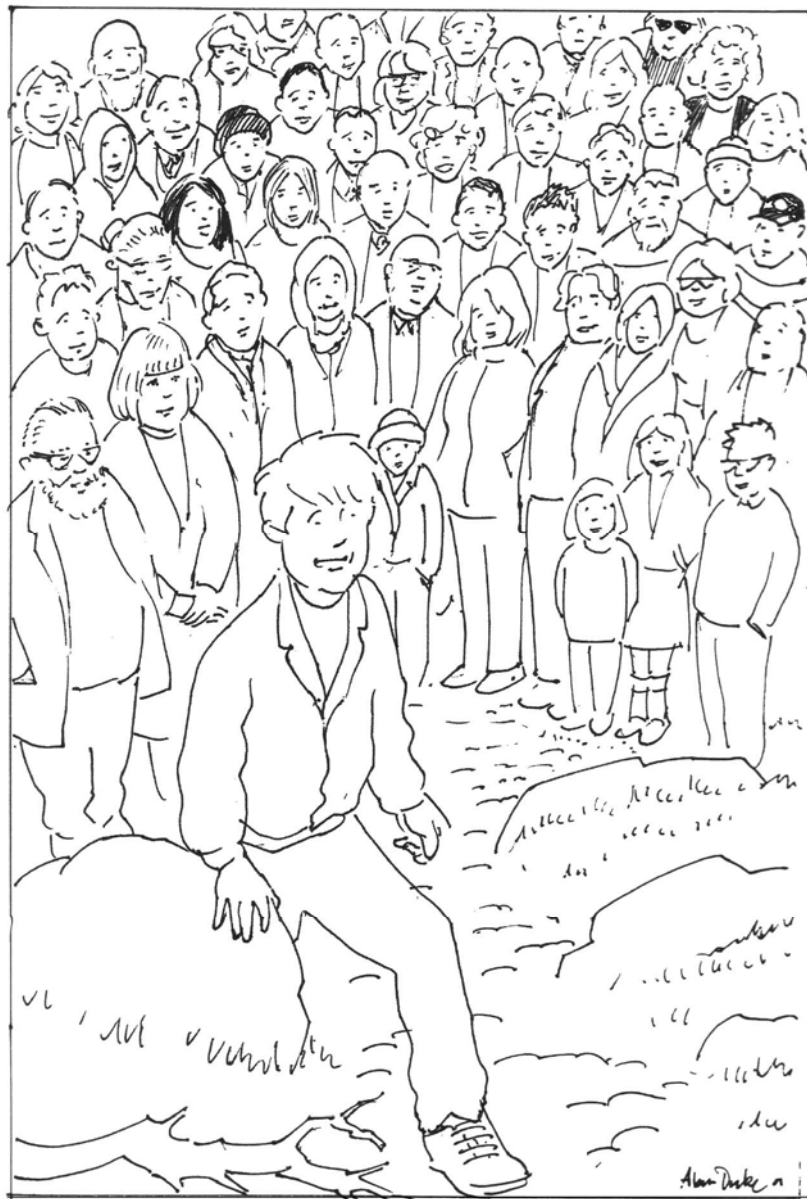
Data presented in this report represent a snapshot of the life of families living with children diagnosed with ASD and show a system that is not working to meet their needs. While many of the key structures are in place, and reflect positive values of people who care, the lack of resources means structures are not functioning effectively. These findings are very worrying given that these issues were identified many years ago in both the Report of the Task Force (2001), the Report of the Task Group on Autism (2002), as well as by the All-Party Parliamentary Group on Autism (APPGA; 2002), and again more recently in a number of government commissioned reports (Bamford & McClelland, 2006; McConkey et al., 2007; ASD Working Group, 2007; O'Connor et al., 2006).

Data-based decision making lies at the heart of a science of behaviour. This means that decisions to implement services should be based on evidence collected (Perry & Condillac, 2003). With so many parents reporting failures of the system, it is time for a re-assessment of service delivery. A number of key issues are associated with high stress levels of parents: If children with ASD can be diagnosed in a matter of weeks in other dedicated centres (e.g., New England Center for Children, 2007; Princeton Child Development Institute, 2007), why is it taking so long in Ireland? Why are there so many variations in duration, and why is there no joined-up thinking to create a coherent system of diagnosis and support? Why is there no comprehensive database for families with children diagnosed with ASD? Why, if the international community understands that science-based treatment is evidently the most effective approach, do parents in Ireland have to pay the price for inaccuracies about ABA in reports?

There was agreement between professionals and parents about the need for future improvements in the diagnostic process, with regard to interventions and therapies, and social supports (cf. Bamford & McClelland, 2006). There was also agreement about the need for better opportunities for inclusion, advocacy, review of care and education plans,

and information flow between parents and professionals, especially with regard to services and financial planning. The scientific method offers a common starting point for a wide range of interventions to meet the spectrum of needs of children with ASD. The time has come for our community to implement the scientific knowledge base of the science of behaviour in order to be able to bring out the best in our children (Figure 8).

**Figure 8: Illustration of a comprehensive support systems** (original work Alan Duke, 2007).



## **14. Recommendations**

### **Diagnosis**

1. That the diagnostic process is shortened to maximum of 90 days, in accord with international guidelines;
2. That internationally recognised measures and assessment tools are used (e.g., ADOS and ADI-R);
3. That all staff involved in diagnosis are trained to international standards in the use of validated and reliable diagnostic measures;
4. That one key worker/advocate be appointed to hold key responsibility for each family/child during and after the diagnostic process;
5. That modern technology be used (e.g., two-way mirrors, video recordings) to reduce the number of professionals to which a child is directly exposed;
6. That localised diagnosis and assessment is made available, in order to prevent unnecessary disruption and allow for a more rapid responsive mode of delivery;
7. That a comprehensive database of children with ASD and their families is established;
8. That the concept of ASD as a necessarily life-long disability be revised in view of intervention data.

### **Early intervention and education:**

9. That SENS s are issued speedily in line with the law (i.e., max 18 weeks);
10. That each child's education and care plan is revised regularly, incorporating parental feedback and data derived from interventions;
11. That intervention begins early (i.e., immediately after diagnosis/before the child's 3<sup>rd</sup> birthday), as recommended by international research and the All-Party Parliamentary Group on Autism (APPGA, 2003).
12. That localised intervention is made available to allow for a data-based, prompt, responsive mode of delivery;
13. That a long-term view is taken on the economic impact of intensive early intervention, i.e., that resource allocation decisions are based on national and international cost-benefit analysis;
14. That all children diagnosed with ASD are offered early intensive behavioural intervention for as long as necessary (in accord with international best practice);
15. That statutory bodies take up their responsibility to supply science-based early intervention, i.e., supply and support ABA-based home tuition programmes and day services;
16. That ABA-based schools and classrooms are developed and maintained by statutory education boards;
17. That all ABA-based intervention is supervised by a BCBA/PhD level trained behaviour analysts;
18. That all staff involved are trained to international standards in ASD and ABA.

### **Staff training:**

19. That accredited Masters level ABA training is fully supported by statutory education and further education bodies;
20. That a range of ASD and ABA training modules and Continuous Professional Development (CPD) courses are developed and supported;

21. That all CPD and short courses in ABA are taught by BCBA/PhD level trained behaviour analysts;
22. That teachers, teaching assistants, and MDT staff are appropriately trained in ASD and ABA;
23. That staff take into account the fact that modern day parents may be better informed than some of the staff on issues regarding ASD and ABA;
24. That ABA is considered for application in other areas of work (e.g., social work, community work, mental health, behavioural medicine) and that staff are educated about ABA in these areas;
25. That further research is carried out to keep abreast with international advances in science regarding ASD and ABA.

**Parent-professional partnership**

26. That parents' input into the writing and review of care and education plans is comprehensively incorporated, and that data from professionally monitored home tuition programmes are included;
27. That parents are kept fully informed regarding financial, social, home, and respite care provisions, and early intervention;
28. That appropriate home, family, respite, and early intervention supports are available to parents and families;
29. That appropriate financial supports are made available to parents and families;
30. That individual and family needs of siblings and parents are considered in assessment and resource allocation;
31. That extended family are fully involved in assessment and intervention, where appropriate;
32. That parent training courses are made available for ASD and ABA, taught by BCBA/PhD level trained behaviour analysts;
33. That parents are fully involved in decision making regarding assessment, review, and intervention;
34. That ABA is accurately presented in reports and review, i.e., that appropriately ABA-trained professionals are included on review boards or are fully consulted;
35. That professional competences and boundaries are respected and professional ethics are adhered to.

In sum, there needs to be a co-ordinated holistic child- and family-centred systemic approach that is underpinned by science and data-based decision making and that is monitored comprehensively.

Knowing is not enough; we must apply. Willing is not enough; we must do. (Goethe, 1749-1832)



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## Glossary of Terms

➤ ABA	Applied Behaviour Analysis
➤ ABA school/class	Provided/supervised by Behaviour Analyst
➤ ABA training	Training provided by Behaviour Analyst
➤ ADHD	Attention Deficit Hyperactivity Disorder
➤ After school club	Provided after school until tea-time
➤ ART	Aggression Replacement Training
➤ ASD	Autism Spectrum Disorder.
➤ Behaviour Analyst	Board Certified Behavior Analyst (BCBA) or PhD-level.
➤ BCABA	Board Certified Associate Behavior Analyst
➤ BCaBA	Board Certified Assistant Behavior Analyst
➤ BCBA	Board Certified Behavior Analyst
➤ BPS	British Psychological Society
➤ CPD	Continuous professional development
➤ Direct Payments	Financial assistance (grant)
➤ DSM-IV	Diagnostic and Statistical Manual – Fourth Edition
➤ DTT	Discrete Trial Training
➤ Family support	Someone paid to help with family/child care
➤ Holiday club	Social and leisure activities
➤ Home help	Someone paid to help with domestic duties
➤ Home-to-home	Short-term care by family member
➤ ICD-10	International Classification of Diseases.
➤ IEP	Individualized Education Plan.
➤ In-home-respite	Short-term care in own home.
➤ MDT	Multi-disciplinary Support and Therapies
➤ MRC	Medical Research Council
➤ NAS	National Autistic Society
➤ N.I.	Northern Ireland
➤ OBM	Organisational Behaviour Management
➤ OCD	Obsessional Compulsive Disorder
➤ Out-of-home respite	Short-term care a designated respite unit
➤ PBS	Positive Behaviour Support
➤ PCP	Person Centered Plan
➤ PECS	Picture Exchange Communication System
➤ PDD	Pervasive Developmental Disorders
➤ R.O.I.	Republic of Ireland
➤ PSI	Psychological Society Ireland
➤ SENS	Special Education Needs Statement
➤ S&L	Speech and Language
➤ Statutory Services	Provided by government.
➤ TEACCH	Treatment and Education of Autistic and related Communication Handicapped Children.
➤ Voluntary Services	Provided by charity or voluntary agency
➤ VBA	Verbal Behaviour

### About the authors

**Dr Mickey Keenan** is a Fellow of the British Psychological Society, Board Certified Behavior Analyst, and Fellow of the Higher Education Academy. He is a Senior Lecturer at the School of Psychology in the University of Ulster. He has received a number of awards for his work in helping families and children with ASD in Ireland, including a *Distinguished Community Fellowship* from the University of Ulster, the *Award for Promoting Equality of Opportunity* from the British Psychological Society, a *Personal Achievement Award* from the New York State Association for Behaviour Analysis, and the *Award for Public Service to Behavior Analysis* from the Society for the Advancement in Behavior Analysis. He has published widely in national and international journals. He is the father of four children.

**Dr Karola Dillenburger** is a Board Certified Behavior Analyst, Chartered Clinical Psychologist, registered social worker, and Fellow of the Higher Education Academy. She is Reader in the School of Sociology, Social Policy and Social Work at Queen's University of Belfast. She has been involved in research regarding parent training and empowerment for many years. She has published widely in national and international journals. She is the mother of four children.

**Alvin Doherty** is a psychologist and was the research associate for the research reported here. He since has returned to his post with the Health Service Executive Western Region as Project Officer in the Learning Disability Services in Letterkenny, Co. Donegal.

**Dr Tony Byrne** is a lecturer in nanotechnology and integrated bioengineering at the University of Ulster. He is the father of five children, two of who were diagnosed with autism spectrum disorder and one with attention deficit hyperactivity disorder. He and his wife have been involved in science-based early intervention for many years and have run extensive home-programmes. He is the Chairperson of the Parents' Education as Autism Therapists Charity.

**Dr Stephen Gallagher** is a Board Certified Behavior Analyst and a lecturer at the School of Psychology at the University of Ulster. Previously, he was Director of Training for the Parents' Education as Autism Therapists Charity where he was involved in parent training and the design of home programmes for early intensive behavioural intervention with children with autism spectrum disorder. His research interests include applied behaviour analysis, autism, gerontology, and social inclusion.

## Appendix 1

**If more than one child in your family has been formally diagnosed with ASD, please complete one questionnaire for each child.**

### Section 1A - Child's Information Background

**Q1. What age is your child?** [                      ] Yrs                      Male                      Female

**Q2. Age of child, when formally diagnosed with Autistic Spectrum Disorder?** [                      ] Yrs

**Q3. On Average, how long did the diagnosis process take before your child was formally diagnosed?** [                      ] Months **OR** [                      ] Years

**Q4. Which of the following formal diagnoses applies to your child?**

*(Please ✓ as appropriate)*

Autism Spectrum Disorder	Pervasive Developmental Disorder – Not otherwise specified (PDD-NOS)
Asperger's Syndrome	Childhood Disintegrative Disorder (CDD)
Rett's Disorder	Don't Know

**Q5. Does your child have any of the following Dual Diagnosis?** *(Please ✓ as appropriate)*

Learning Disability	Yes	No	If yes? Please specify (i.e. mild / moderate etc....) [                      ]
Physical & Sensory	Yes	No	If yes? Please specify (i.e. Visual / Physical etc....) [                      ]
Other?	Yes	No	If yes? Please specify (i.e. ADHD / epilepsy etc....) [                      ]

*\* If residing in the Republic of Ireland, please go straight to Q7.*

*(Please ✓ as appropriate)*

	Yes	No	Don't Know
<b>Q6. (A) Does your child have a Special Education Needs Statement?</b>			

*If Yes, please answer Q6. B, C, D, E. If No, please answer Q6. F & G.*

**Q6. (B) What age was your child when he/she formally received their Special Education Needs Statement?**

[                      ] Years

**Q6. (C) On Average, how long did the process take ?**

[                      ] Months

	Yes	No
<b>Q6. (D) Do you feel your Child's educational statement <u>accurately</u> describes his/her individual needs?</b>		
<b>Q6. (E) Do you feel the provisions outlined in your Child's educational statement are <u>appropriate</u> to his/her needs</b>		
<b>Q6. (F) Is your child currently in the process of being issued an Special Education Needs Statement?</b>		
<b>Q6. (G) On average, how long is this process taking?</b>	[                      ] Months	



**Q7. What is your child's current residential circumstance? (Please ✓ as appropriate)**

At Home with Both Parents	Living at Home with Extended Family
At Home with One Parent	Living at Home with Non Relative
At Home with Foster Parent	Living in Residential / Group Home
At Home with Adopted Parent	Living in Shared Care / Guardianship
Other: [ ]	

**Q8. Does this child, have any other brothers or sisters? Yes No**  
(If yes, please specify)

Number of brothers	[ ]	Ages: [ ]Yrs	[ ]Yrs	[ ]Yrs
Number of sisters	[ ]	Ages: [ ]Yrs	[ ]Yrs	[ ]Yrs
Number of brothers and sisters living at home [ ]				

**Q9. Do any of your other children have a formal Clinical Diagnosis? Yes No**

If Yes, please specify: Diagnosis [ ] Age [ ] Yrs Male Female

**Section 1B - Parental Information****Q10. What is your age?** [ ] Yrs Male Female**Q11. Are you the Primary Caregiver for this child?** Yes No**Q12. Is your family?** A Single Parent family **OR** Two parent family**Q13. What is your relationship with the child? (Please ✓ as appropriate)**

Mother	Grandparent	Foster Parent
Father	Guardian / Carer	Sibling

**Q14. What is your current Marital Status? (Please ✓ as appropriate)**

Married / Cohabiting Single Divorced Widowed

**Q15. (A) Please describe you and your partners current Occupational Status?**

(Please ✓ as appropriate)

	Unemployed?	Employed Part-Time?	Employed Full-Time?	What is your Occupation?	Hours worked Per Week
Yourself				[ ]	[ ]
Partner				[ ]	[ ]

\* If you and your partner are both employed full time, please go to **Q16.**\* If either you or your partner are part-time employed or unemployed, please answer **Q15. (B) & (C)**

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**Q15. (B) Have you or your partner ever been employed Full-Time in the past?** Yes No

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**Q15. (C) Has your or your partner's commitment to your Child's care affected your/ their availability for full-time employment?** Yes No

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**Q16. What is your highest educational obtainment?** (i.e. A-Levels / Leaving Certificate / Degree etc.)

Northern Ireland: Please specify

[ ]

Republic of Ireland: Please specify

[ ]

**Q17. Are you a member of any charity organisation of parents group for children with ASD?** Yes No If yes, please specify [ ]

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**Q18. Where do you currently reside?** (Please ✓ as appropriate)

Northern Ireland → Postal Code (First 2 digits only) BT [ ]

Republic of Ireland → Name of County: [ ]

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**Q19. Do you suffer from any of the following chronic health problems?** (Please ✓ as appropriate)

Yes	Yes	Yes
Arthritis	Hearing	Psychiatric Illness
Asthma	Heart Related	Physical Disability
Diabetes	Epilepsy	Visual Impairment
Other, please specify: [ ]		Not Applicable

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## Section 2 - Child's Education Provision

Please note during section 2. The letters BCBA in \*Qualified Behaviour Analyst' - Trained to BCBA / PHD level in Applied Behaviour Analysis signify 'Board Certified Behaviour Analyst' (BCBA).

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## Section 2A - ASD Home Tuition Programmes

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**Q20. Is your child receiving any of the following ASD Home Tuition Programmes?** (Please ✓ As appropriate)

Applied Behaviour Analysis (ABA)	Other, please specify: [ ]
TEACCH	* Not delivering any home tuition programme

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\* If you are not delivering any Home Tuition Programme at present, please go to **Question 27**.

**Q21. How did you become aware of the Home Tuition Programmes available for children with ASD?** (Please ✓ As appropriate)

From statutory professionals	From friends & family
Personal research	From other parents of children with ASD
Other, please specify: [ ]	

**Q22. Please answer the following in respect of your child's ASD Home Tuition Programme?**

How long have you been delivering this programme?	[ ] Months or [ ] Yrs
What age was your child when you started the programme?	[ ] Yrs

**Q23. How is your child's ASD Home Tuition Programme presently delivered?**

(Please ✓ As appropriate)

	Yes	Hours delivered by you per week	Hours delivered by other per week
By yourself		[ ]	Not Applicable
By you and your Partner		[ ]	[ ]
* By you and a Qualified Behaviour Analyst		[ ]	[ ]
* By a Qualified Behaviour Analyst only		Not Applicable	[ ]
By you and a Home Tutor		[ ]	[ ]
By you and your child's school		[ ]	[ ]
By you and extended Family members		[ ]	[ ]
Other, please specify: [ ]		[ ]	[ ]

\* Qualified Behaviour Analyst - Trained to BCBA / PHD level in Applied Behaviour Analysis

**Q24. Which of the following are used to monitor you child's Home Tuition Programme?** (Please ✓ As appropriate)

	Yes		Yes
Graphs / Observational Charts		Notes / Commentaries	
Tables		Other. please specify: [ ]	
*Supervision for Home tuition programme is provided by a Qualified Behaviour Analyst			
No methods are currently used to monitor child's ASD Home Tuition Programmes			

\* Qualified Behaviour Analyst - Trained to BCBA / PHD level in Applied Behaviour Analysis

**Q25. On average, how much do you personally spend on the provision of home tuition per annum?** € / £ [ ]

Q26. Do you consider your child's ASD Home Tuition Programme appropriate to his/her needs? (Please ✓ As appropriate)	Always	Sometimes	Never	Don't Know

Please provide any comments you may have relating to Q26:



(Please ✓ As appropriate)

**Please note, when completing Sections 2B & 2C and Sections 3A & 3B**

- Your child receiving educational services each week, constitutes your child being "in receipt of" that service;
- The availability of respite 1 or 2 nights a year does **NOT** constitute your child being in receipt of that service;
- Having an appointment with an educational psychologist once in the last 12 months does **NOT** constitute your child being "in receipt of" this multidisciplinary therapy.

The phrase "**within the next five years**" should reflect the year in which you require services to be in place (this can be any year between 2007-2012).

**Q34. Which of the following educational or day service provisions does your child currently receive?** (Please ✓ As appropriate)

*\*If your child currently receives Home Tuition only, please go to **Q40**.*

Services (Please tick appropriate)			
	Yes		Yes
<b>A:</b> Special Needs School		<b>E:</b> *ABA Specific School	
<b>B:</b> Special Needs Class in Mainstream School		<b>F:</b> *ABA Specific Class in Mainstream School	
<b>C:</b> Mainstream Class		<b>G:</b> Adult Day Service	
<b>D:</b> ABA Specific Class in Mainstream School		<b>H:</b> Rehabilitative Training	

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**Q35 (B). Please indicate the level your child currently receives their education or day service provision?** (Please ✓ As appropriate)

Pre-School Level		Primary School Level		Secondary School Level		Adult Day Services(18+YRS)	
Yes		Yes		Yes		Yes	

**Q35 (C ).How many hours per week does your child attend the above day services? [ ]Hrs**

Q36. Please indicate the level of educational or day service support currently received by your child? (i.e. 1 staff member to every 3 children = 1:3)	Ratio	Don't Know	Not Applicable
	__ : __		

**Q37. Which of the following methods are used to monitor you child's Educational Provision?**

(Please ✓ As appropriate)	Yes	Don't Know		Yes	Don't Know
Graphs / Observational Charts			*Supervision provided by qualified Behaviour Analyst		
Tables			Other, please specify: [ ]		
Staff Notes / Commentaries					

\* Qualified Behaviour Analyst- Trained to BCBA / PHD level in Applied Behaviour Analysis

**Q38. On average, what distance (return journey) does your child travel to his/her current education or day service provision each day? [ ] Miles**

**Q39. Do you consider your child's current educational or day service provision appropriate to his/her needs?**

(Please ✓ As appropriate) Always Sometimes Never Don't Know

(Please ✓ As appropriate) Yes No Undecided

**Q40 (A). Will you require a different educational or adult day service provision for your child within the next 5 years?**

*\*If No or Undecided: please go to Q43.*

**Q40 (B). If Yes. which of the following educational or day service (18+yrs) provisions will you require for your child within the next 5 years?**

(Please ✓ As appropriate)	Yes		Yes
<b>A:</b> Special Needs School		<b>E:</b> *ABA Specific Class in Mainstream School	
<b>B:</b> Special Needs Class in Mainstream School		<b>F:</b> *ABA Specific School	
<b>C:</b> Mainstream Class		<b>G:</b> Young person requires Adult Day Service	
<b>D:</b> ABA Specific Class in Mainstream School		<b>H:</b> Young person requires Rehabilitative Training	

\* Teaching and educational provision provided by a Qualified Behaviour Analyst - Trained to BCBA / PHD level in Applied Behaviour Analysis

**Q40 (C). Please indicate the level you require the above education or day service provision to be delivered?** (Please ✓ As appropriate)

<b>Pre-School Level</b>	<b>Primary School Level</b>	<b>Secondary School Level</b>	<b>Adult Day Services</b>
Yes	Yes	Yes	Yes

**Q40 (D ).How many hours per week does your child require the above a day service?**

Hours

<b>Q41. Please indicate the level of educational or day service support required for your child in the future?</b>	Ratio	Don't Know	Not Applicable
(i.e. 1 staff member to every 5 children = 1:5)	__ : __		

**Q42. In which year is the above educational / adult day service provision required?** [ ]

**Q43. How did you become aware of the Educational Provisions available to your child with ASD?** (Please ✓ As appropriate)

From statutory professionals		From friends & family	
Personal research		From other parents of children with ASD	
Other, please specify: [ ]			

(Please ✓ As appropriate)

	Yes	No
<b>Q44. Have you ever considered moving your family in order to avail of educational provision more appropriate to your child's needs?</b>		

<b>Q45. Have you moved your family in order to avail of educational provisions more appropriate to your child's needs?</b>		
----------------------------------------------------------------------------------------------------------------------------	--	--

\* If your child receives Home Tuition Only, please answer **Q46 Table C** (only) and then go to **Q47**.

**Q46. Table A. Please indicate the highest level of Higher Education / Professional Qualifications:**

**(A)** held by your child's current Teacher & Assistants? and

**(B)** the level of Higher Education / Professional Qualifications you think staff require in the future?

<b>Table A</b>				
(Please ✓ As appropriate)				
	<b>Teacher Training</b>		<b>Educational Assistants</b>	
	<b>A. Held</b>	<b>B. Required</b>	<b>A. Held</b>	<b>B. Required</b>
	Yes	Yes	Yes	Yes
Don't Know				
Degree Level				
Masters Level				
Masters Level in Autism Spectrum Disorders				
Masters - ABA				
PHD - ABA				
Board Certified Behaviour Analyst				
Board Certified Associate Behaviour Analyst				
Other, [ ]				

**Q46. Table B. Please indicate the types of Additional training received by your child's current Teacher and Assistant?**

<b>Table B</b>			
<b>Teacher Training</b> (Please ✓ As appropriate)	Conference Workshops	Short Courses	*1:1 Supervision by Behaviour Analyst
Don't know			
Training in Autistic Spectrum Disorders			
* Training in ABA			
Other: [ ]			
<b>Educational Assistants</b> (Please ✓ As appropriate)	Conference Workshops	Short Courses	*1:1 Supervision by Behaviour Analyst
Don't know			
Training in Autistic Spectrum Disorders			
* Training in ABA			
Other: [ ]			
* Delivered by a Qualified Behaviour Analyst - Trained to BCBA / PHD level in ABA			

**Q46. Table C. Please indicate the types of Additional training you believe are required for future Teachers and Assistants educating your child ?**

<b>Table C</b>			
<b>Teacher Training</b> (Please ✓ As appropriate)	Conference Workshops	Short Courses	*1:1 Supervision by Behaviour Analyst
Training in Autistic Spectrum Disorders			
* Training in ABA			
Other:[ ]			
<b>Educational Assistants</b> (Please ✓ As appropriate)	Conference Workshops	Short Courses	*1:1 Supervision by Behaviour Analyst
Training in Autistic Spectrum Disorders			
* Training in ABA			
Other: [ ]			
* Delivered by a Qualified Behaviour Analyst - Trained to BCBA / PHD Level in ABA			

**Section 2C - Child's Financial Support**

<b>Q47. Please answer the following:(Please ✓ As appropriate)</b>	Yes	No	Not Applicable
<b>A.</b> Have statutory services informed you of any financial supports available to your child and family?			
<b>B.</b> If you have been informed, have you agreed to avail of these financial supports?			



**Q48. Please answer the following in respect of:**

- (A) The financial supports your child currently receives?, and  
 (B) The financial support your child requires in the next five years?

(Please ✓ as appropriate)	(A) Supports currently received		(B) Supports required in future	
	Yes	Average Amount Per Year	Yes	Average Amount Per Year
Child's School Fees are paid for		€ /£ [      ]		€ /£ [      ]
Child's Full-Time Home Tuition Fees are paid for		€ /£ [      ]		€ /£ [      ]
Home Tutor Fees are paid for		€ /£ [      ]		€ /£ [      ]
Transport Costs		€ /£ [      ]		€ /£ [      ]
Medical Card		€ /£ [      ]		€ /£ [      ]
Disability Allowance		€ /£ [      ]		€ /£ [      ]
Respite Care Grant (Direct Payment)		€ /£ [      ]		€ /£ [      ]
Mobility Allowance		€ /£ [      ]		€ /£ [      ]
Other currently received, please specify: [                                      ]		€ /£ [      ]	N/A	Not Applicable
Other required for future, please specify: [                                      ]				€ /£ [      ]
In which year is the above financial supports required? [              ] Year				

**Q49. Please answer the following in respect of:**

- (A) The agencies currently providing your child with financial support?, and  
 (B) The agencies you require Financial Support from within the next five years?

(Please ✓ as appropriate)	(A) Funding currently received		(B) Funding required in future	
	Yes	Average Amount Per Year	Yes	Average Amount Per Year
No Financial Support received		Not Applicable	N/A	Not Applicable
Local Education & Library Board (LELB)		€ /£ [      ]		€ /£ [      ]
Local Health & Social Services		€ /£ [      ]		€ /£ [      ]
Department of Education (Republic of Ireland)		€ /£ [      ]		€ /£ [      ]
Health Service Executive (Republic of Ireland)		€ /£ [      ]		€ /£ [      ]
Voluntary Organisation, please specify: [                                      ]		€ /£ [      ]		€ /£ [      ]
Other received: please specify [                                      ]		€ /£ [      ]	N/A	Not Applicable
Other required in Future, please specify: [                                      ]				€ /£ [      ]

### Section 3A - Health & Social Services Financial Supports

**Q51.** Please answer the following in respect of:

**(A)** The types of Multidisciplinary Services (MDT) your Child currently receives, and  
**(B)** The types of Multidisciplinary Services (MDT) your Child requires in the next five years?

*\*If you are not currently receiving or availing of any Multidisciplinary Services (MDT) please complete **Table 1 part (B) only.***

### Section 3B - Health & Social Services: Home & Respite Supports

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**Q53. Please answer the following in respect of:**

- (A) The types of Home and Respite Supports your Child Currently receives?, and  
 (B) The type of Home and Respite Supports your child requires in the next five years?

*\*If you are not currently receiving or availing of any Home or respite supports, please complete Table 1 Part (B) only.*

<b>Table 1</b>	<b>(A) Currently Received</b>		<b>(B) Required in Future</b>	
<b>Home Support Services</b> (Please ✓ As appropriate)	Yes	Hours Per Month	Yes	Hours Required Per Month
<u>Home Help / Domiciliary Care</u> : Someone is paid to come to your home and help with domestic duties.		[       ] Hours		[       ] Hours
<u>Home Support / Family Support</u> : Assistance provided to the family in terms of assisting in care, facilitating attendance at social activities. Usually provided after 5pm, this is a funded service. <i>Organized via local Health service.</i>		[       ] Hours		[       ] Hours
<u>Direct Payments</u> : You are directly provided with financial assistance (grant) from statutory services to organize and pay for your own Home Support.		[       ] Hours		[       ] Hours
None of the above Support Services are received.				
In which year is the above Home supports required? [       ] Year				Not Applicable
<b>Table 1 (continued.....)</b>	<b>(A) Currently Received</b>		<b>(B) Required in Future</b>	
<b>Respite Support Services</b> (Please ✓ As appropriate)	Yes	Hours Per Month	Yes	Hours Rq Per Month
<u>Out of Home Respite (Crisis &amp; Planned)</u> : Child is cared for in designated Respite Unit / Facility.		[       ] Hours		[       ] Hours
<u>In Home Respite (Crisis &amp; Planned)</u> : Someone is paid to visit your home and provide assistance with your child. <i>Organised via local Health Service.</i>		[       ] Hours		[       ] Hours
<u>Home to Home Scheme (Crisis &amp; Planned)</u> : Another family volunteers to care for your child on a respite basis. <i>Organised via local Health Service.</i>		[       ] Hours		[       ] Hours
<u>Summer / Easter Club</u> : Provisions are made for your child to attend social and leisure activities during the holiday period.		[       ] Hours		[       ] Hours
<u>After school Club</u> : Provisions are made for your child to attend an after school club in designated unit / facility.		[       ] Hours		[       ] Hours
None of the above Respite Services are received.				
In which year is the above Respite supports required? [       ] Year				Not Applicable

*(Please ✓ As appropriate)*

	Always	Sometimes	Never	Don't Know	N / A
<b>Q54. Do the Home Supports provided to you and your child meet your needs?</b>					
<b>Q55. Do the Respite Supports provided to you and your child meet your needs?</b>					

(Please ✓ As appropriate)		Yes	No	Average Hours Per Month	
Extended Family – Parents / Sisters / Brothers				[ ]	[ ]
Friends				[ ]	[ ]
Voluntary Organisations please specify: [ ]				[ ]	[ ]

**Q57. Does your child have any of the following Care Plans in place as part of his/her Educational or Health Care Provision?** (Please  $\checkmark$  as appropriate)

Additional or Health Care Provision (Please V as appropriate)	Yes	* Don't Know
Person Centred Plan (P.C.P.) (Health)		
Individual Educational Plan (I.E.P.) (Education)		
Other, please specify: [ ]		

\* Child has No Care Plans in Place

**Q58. Which of the following Professionals are involved in the planning and review of your child's Care Plan?**

(Please ✓ as appropriate)		Yes	Yes
*Behaviour Analyst		Social Work	
Child's Teacher		Nursing	
Occupational Therapy		Psychiatry	
Physiotherapy		Speech & Language	
Clinical Psychologist		Autism Therapist	
Educational Psychologist		Other:	
		[ ]	
*Behaviour Analyst - Therapist trained to BCBA / PHD Level in Applied Behaviour Analysis			

A. Every [            ] Months.                      B. Don't Know

<b>Please answer the following:</b> <i>(Please ✓ As appropriate)</i>	Always	Sometimes	Never	
<b>A.</b> Are you invited to be involved in the review of your child's Care Plan?				N/A
<b>B.</b> If invited, do you agree to be involved in the review?			*	N/A
<i>*If you have answered NEVER to Q59 B, please go to Q60</i>	Always	Sometimes	Never	Don't Know
<b>C.</b> If you attend, do the professionals include your choices and opinions as part of the Care Plan review?				
<b>D.</b> If you attend, do professionals consider any data(Graphs/Charts, etc.) used to monitor your child's educational progress as part of the Care Plan review?				
<b>E.</b> If you attend, do professionals consider any data(Graphs/Charts, etc.) used to monitor your child's ASD Home Tuition Programme as part of the Care Plan Review?				
<b>F.</b> If you attend, do professionals explain what methods are used to determine when targets and objectives of the care plan are met?				
<b>G.</b> Do you consider your child's Care Plan appropriate to his/her individual needs?				

## Section 5 - Parental Experiences & Views

### Q60. Please answer the following questions in respect of your experiences?

(Please ✓ as appropriate)

1. My child's diagnosis was completed in a timely and professional manner?

Agree Completely	Agree	Neutral	Disagree	Completely Disagree

2. The information I received on my child's diagnosis was clearly presented and easily understood?

Agree Completely	Agree	Neutral	Disagree	Completely Disagree

3. Following my child's diagnosis, I received sufficient support and advice regarding the services available to my child and family?

Agree Completely	Agree	Neutral	Disagree	Completely Disagree

4. Following my child's diagnosis, I received sufficient information and advice regarding the financial entitlements available to my child and family?

Agree Completely	Agree	Neutral	Disagree	Completely Disagree

### Q61. Have you ever experienced emotional distress or difficulties with any of the following Behaviours your child may exhibit?

(Please ✓ as appropriate)

	Yes		Yes
Erratic sleep patterns		Language and communication problems	
Weight control		Behaviours that challenge	
Strict compliance to routine Behaviour		Deficits in self - help skills	
Excessive ritualistic Behaviours		Lack of interaction / play with other children	
Sexual Behaviours		Lack of interaction with parents	
Deficits in social skills		ADHD	
Other Behaviours, please specify: [ ]			

### Q62. Do you feel your other children ever experience any of the following feelings as a result of your Child's ASD condition?

(Please ✓ as appropriate)

	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Feelings of being neglected					
Are worried and anxious about their sibling's condition					
Feelings of resentment towards child with ASD					
Feelings of guilt and fears they may be responsible somehow					
Feelings of being treated unfairly					
Feelings of isolation from peers					
Are more willing to help with chores					
Are very sensitive to sibling's needs					
Are very sensitive to the needs of others					
Actively engage with sibling					

<b>Q63. Do you feel your child's condition restricts your <i>Personal</i> ability to plan and pursue the following?</b>					
<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Educational interests					
Occupational and employment interests					
Social and community interests?					
Recreational and leisure interests?					

<b>Q64. Do you feel your child's condition restricts your <i>family's</i> ability to plan and pursue the following?</b>					
<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Recreational and leisure interests for family					
Social and community interests for family					
Holidays / family excursions					

<b>Q65. Do you feel your Child's condition restricts the amount of quality time you can <i>Personally</i> spend with the following people?</b>					
<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Your partner					
Your other children					
Your extended family and friends					

<b>Q66. How would you rate your general level of stress?</b> <i>(Please ✓ as appropriate)</i>		
Highly Stressed	Quite Stressed	Not stressed at all

<b>Q67. How long have you felt this way?</b>	
[            ] Months <b>OR</b> [            ] Years	Not Applicable

(Please ✓ as appropriate)	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Increase support and guidance during the diagnosis process					
Increased opportunities for *ABA Specific Schooling					
Opportunities for General Parent Training in *ABA					
Opportunities for General Siblings Training in *ABA					
Opportunities for General Parent Training in TEACCH					
Opportunities for General Parent Training in ASD					
Increased provisions of Multidisciplinary Supports					
Increased Home and Respite Supports					
The Appointment of a Family Advocate					
The need for a structured and comprehensive Care Plan to address your child's future needs					
Increase parental involvement in the creation and review of Care Plans					
Increased opportunities for your ASD child to participate in Community & Social Activities					
Increased parental choice in the recruitment and appointment of Home Support Workers					
Greater sharing of information between professionals					
Professional advice on entitlements available to your family					
Professional advice on financial planning for a Child's future					
Other: [ ]					

**Q69. Have you ever considered the application of Applied Behaviour Analysis to:**

**(B)** Do you feel the availability of more information in these areas would be beneficial?

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**Q70. We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by circling the answer which you think most nearly applies to you. Remember that we want to know about the present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.**

HAVE YOU RECENTLY:				
	<i>Please CIRCLE one answer for each Question</i>			
1. Have you recently: been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Have you recently: lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Have you recently: felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Have you recently: felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5. Have you recently: felt constantly under strain?	Not at all	No More than usual	Rather more than usual	Much more than usual
6. Have you recently: felt you couldn't overcome your difficulties?	No at all	No more than usual	Rather more than usual	Much more than usual
7. Have you recently: been able to enjoy your normal day today activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Have you recently: been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
9. Have you recently: been feeling unhappy or depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Have you recently: been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Have you recently: been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Have you recently: been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
© David Goldberg, 1978				

**On behalf of the Charity: Parents' Education as Autism Therapists (P.E.A.T.), the University of Ulster and Queens University Belfast, we would like to thank you for your time in completing this questionnaire and your willingness to participate in the research project.**

**Thank you**



## Appendix 2

### Professional Questionnaire: Section 1

**Q1. Gender** (Please ✓ as appropriate) ☐ Male ☐ Female

**Q2: What is your highest educational attainment?** (i.e.: Degree Level / Masters Level / PHD Level)  
Please specify:

**Q3. Where are you currently employed?** (Please ✓ as appropriate) Yes

Northern Ireland	<input type="checkbox"/>
Republic of Ireland	<input type="checkbox"/>

**Q4. Which of the following organisations are you currently employed by?**  
(Please ✓ as appropriate)

Education & Library Board (LELB)	<input type="checkbox"/>	Health Service Executive (Republic of Ireland)	<input type="checkbox"/>
Health and Social Services Service Trust	<input type="checkbox"/>	Department of Education (Republic of Ireland)	<input type="checkbox"/>
Voluntary Organisation: Please specify	<input type="checkbox"/>	Other: Please specify	<input type="checkbox"/>

**Q5. What is your current profession?** (Please ✓ as appropriate)

	Yes		Yes
*Behaviour Analyst	<input type="checkbox"/>	Social Work	<input type="checkbox"/>
Teacher	<input type="checkbox"/>	Paediatrician	<input type="checkbox"/>
Special Educational Needs Teacher	<input type="checkbox"/>	Psychiatry	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	Speech & Language	<input type="checkbox"/>
Clinical Psychologist	<input type="checkbox"/>	Autism Therapist	<input type="checkbox"/>
Educational Psychologist	<input type="checkbox"/>	Public Health Nurse	<input type="checkbox"/>
Nurse: Learning Disability	<input type="checkbox"/>	Nurse: Mental Health	<input type="checkbox"/>
Medical Services (GP)	<input type="checkbox"/>	Occupational Therapist	<input type="checkbox"/>
Other : Please specify			<input type="checkbox"/>
* Behaviour Analyst = Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)			

**Q6. On Average, how long have you been employed in this position?** Months

**Q7. Is your service?** (Please ✓ as appropriate)

Autism Specific	<input type="checkbox"/>	Generic Services: with ASD Focus	<input type="checkbox"/>
Other: Please specify			

**Q8.What area of service provision are you involved in?** (Please ✓ as appropriate)

Mainstream Education	<input type="checkbox"/>	Assessment	<input type="checkbox"/>
Special Needs Education	<input type="checkbox"/>	Multidisciplinary Team	<input type="checkbox"/>
Autism Specific Education	<input type="checkbox"/>	Early Intervention Team	<input type="checkbox"/>
Adult Day services	<input type="checkbox"/>	Residential & Respite Services	<input type="checkbox"/>
Other: Please specify			<input type="checkbox"/>

**Q9. What percentage of your caseload is specific to ASD Children and Young adults?**

(Please ✓ as appropriate)

100 %	<input type="checkbox"/>	50%	<input type="checkbox"/>	10% of less	<input type="checkbox"/>
75%	<input type="checkbox"/>	25%	<input type="checkbox"/>	Not Applicable	<input type="checkbox"/>

**Q10.Which of the following groups does your ASD caseload apply to?** (Please ✓ as appropriate)

0-6yrs	<input type="checkbox"/>	7-12yrs	<input type="checkbox"/>	13-18yrs	<input type="checkbox"/>	+18 yrs	<input type="checkbox"/>	All Ages	<input type="checkbox"/>	N/A	<input type="checkbox"/>
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**Section 2. ASD Home tuition programmes**

Please Note,

- ABA = The Applied Branch of a science called Behaviour Analysis. For more information please view [www.behavior.org](http://www.behavior.org).
- BCBA = Board Certified Behaviour Analyst (BCBA)

**Q11. Have you ever been personally involved in the delivery of ASD Specific Home tuition programmes for families?** Yes ☐ No ☐ \*If No, please go to **Q14****Q12. Which of the following ASD Home Tuition programmes have you been personally involved in delivering with families?** (Please ✓ As appropriate)

Applied Behaviour Analysis (ABA)	<input type="checkbox"/>	TEACCH	<input type="checkbox"/>
Other, please specify:			<input type="checkbox"/>

**Q13. Please answer the following in respect of your ASD Home Tuition Programme delivery?**

(Please ✓ as appropriate)

How long have you been delivering this programme? Months

What is the average age of the children when you start the programme? Years

**Q14. Have you ever received training in the delivery of ASD Specific Home tuition programmes for families?** Yes ☐ \*No ☐ \*If No, please go to **Q19**

<b>Q15. Please indicate the level of ASD home tuition programme training you have received?</b>				
<i>(Please ✓ As appropriate)</i>	Conference Workshops	Short Courses	*1:1 Supervision by Behaviour Analyst	Average Hours of Training Received
Training In Autistic Spectrum Disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hrs
*Training In ABA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hrs
Training in TEACCH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hrs
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hrs
Training and supervision provided by a Qualified Behaviour Analyst- Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)				

<b>Q16. Have you received training in any of the following methods used to monitor a child's Home tuition programme?</b>			
<i>(Please ✓ As appropriate)</i>	Yes		Yes
Single case designs	<input type="checkbox"/>	Notes / commentaries	<input type="checkbox"/>
Tables Figures	<input type="checkbox"/>	No training received on monitoring methods	<input type="checkbox"/>
Other: Please specify:			<input type="checkbox"/>

<b>Q17. Do you feel your training has provided you with the skills to successfully deliver an ASD home tuition programme?</b> <i>(Please ✓ As appropriate)</i>	Always	Sometimes	Never	Don't Know
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q18. Have your skills in delivering a ASD Home Tuition Programme been assessed?**

Yes ☐ \*No ☐ \* If No, please go to Q19

<b>If yes, which of the following methods were used to assess your skills?</b>			
<i>(Please ✓ As appropriate)</i>	Yes		Yes
Written Examination	<input type="checkbox"/>	Competency- Based Training	<input type="checkbox"/>
Multiple Choice Test	<input type="checkbox"/>	Other:	<input type="checkbox"/>

**Q19. Have you ever studied Applied Behaviour Analysis as part of your Undergraduate or Postgraduate education?** Yes ☐ No ☐

<b>Q20. Please indicate the level training; you feel is required for professionals to deliver ASD Home tuition programmes in the future?</b>			
<i>(Please ✓ As appropriate)</i>	Conference Workshops	Short Courses	Postgraduate/ Msc Level
Training In Autistic Spectrum Disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
*Training In ABA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training in TEACCH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* Training and supervision to be provided by a Qualified Behaviour Analyst - Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)			

**Q21. As a professional, have you ever considered the application of Applied Behaviour Analysis to:**

**(A)** Any of the following areas? and

**(B)** Do you feel the availability of more information in these areas would be beneficial to your profession?

<i>(Please ✓ As appropriate)</i>	A. Yes	B. More Info		A. Yes	B. More Info
Conduct Disorders	<input type="checkbox"/>	<input type="checkbox"/>	General Learning Disabilities	<input type="checkbox"/>	<input type="checkbox"/>
ADHD	<input type="checkbox"/>	<input type="checkbox"/>	General Parenting Skills	<input type="checkbox"/>	<input type="checkbox"/>
School Education	<input type="checkbox"/>	<input type="checkbox"/>	Aggression Replacement training	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	Anxiety and Phobias	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Problems	<input type="checkbox"/>	<input type="checkbox"/>	Obsessive Compulsive Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Self Control	<input type="checkbox"/>	<input type="checkbox"/>	Bereavement	<input type="checkbox"/>	<input type="checkbox"/>
Sexual Behaviours	<input type="checkbox"/>	<input type="checkbox"/>	Marital Therapy	<input type="checkbox"/>	<input type="checkbox"/>
Social skills	<input type="checkbox"/>	<input type="checkbox"/>	Anti -Social Behaviour	<input type="checkbox"/>	<input type="checkbox"/>
Weight Control	<input type="checkbox"/>	<input type="checkbox"/>	Paediatrics	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health	<input type="checkbox"/>	<input type="checkbox"/>	Addictions (i.e. Drugs / Alcohol / Gambling)	<input type="checkbox"/>	<input type="checkbox"/>
Using Single-Case designs	<input type="checkbox"/>	<input type="checkbox"/>	Behaviours that Challenge	<input type="checkbox"/>	<input type="checkbox"/>

**Section 3. Professional Experiences**

**Q22. In your experience, have you noted parents of ASD children experiencing significant distress or difficulties accessing the following services? (Please ✓ as appropriate).**

<i>(Please ✓ as appropriate)</i>	Yes		Yes
Formal Diagnoses	<input type="checkbox"/>	Medical Services (GP)	<input type="checkbox"/>
Educational Provisions	<input type="checkbox"/>	Occupational Therapy	<input type="checkbox"/>
Educational funding	<input type="checkbox"/>	Physiotherapy	<input type="checkbox"/>
Early Intervention Services	<input type="checkbox"/>	Social Work	<input type="checkbox"/>
Homes Supports	<input type="checkbox"/>	Paediatrician	<input type="checkbox"/>
Residential and Respite Supports	<input type="checkbox"/>	Psychiatry	<input type="checkbox"/>
Clinical Psychologist	<input type="checkbox"/>	Speech & Language	<input type="checkbox"/>
Educational Psychologist	<input type="checkbox"/>	Autism Therapist	<input type="checkbox"/>
* Behaviour Analyst	<input type="checkbox"/>	Public Health Nurse	<input type="checkbox"/>
Nursing	<input type="checkbox"/>	Nurse: Mental Health	<input type="checkbox"/>
Special Educational Needs Teacher	<input type="checkbox"/>	Other:	<input type="checkbox"/>

\* Behaviour Analyst = Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)

**Q23. In your professional opinion, which of the following professions would define an appropriate package of Multidisciplinary support for families with ASD?**

<i>(Please ✓ more than one)</i>	Yes		Yes
* Behaviour Analyst	<input type="checkbox"/>	Social Work	<input type="checkbox"/>
Occupational Therapy	<input type="checkbox"/>	Paediatrician	<input type="checkbox"/>
Special Educational Needs Teacher	<input type="checkbox"/>	Psychiatry	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	Speech & Language	<input type="checkbox"/>
Clinical Psychologist	<input type="checkbox"/>	Autism Therapist	<input type="checkbox"/>
Educational Psychologist	<input type="checkbox"/>	Public Health Nurse	<input type="checkbox"/>
Nurse: Learning Disability	<input type="checkbox"/>	Nurse: Mental Health	<input type="checkbox"/>
Medical Services (GP)	<input type="checkbox"/>	Other:	<input type="checkbox"/>

\* Behaviour Analyst = Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)

**Q24. In your experience, have you noted parents of ASD children experiencing emotional distress or difficulties coming to terms with the following behaviours?**

<i>(Please ✓ as appropriate)</i>	Yes		Yes
Erratic Sleep patterns	<input type="checkbox"/>	Language and communication problems	<input type="checkbox"/>
Weight Control	<input type="checkbox"/>	Behaviours that challenge	<input type="checkbox"/>
Strict compliance to routine behaviour	<input type="checkbox"/>	Deficits in self - help skills	<input type="checkbox"/>
Excessive ritualistic behaviours	<input type="checkbox"/>	Lack of interaction / play with other children	<input type="checkbox"/>
Sexual Behaviours	<input type="checkbox"/>	Lack of interaction with parents	<input type="checkbox"/>
Deficits in Social skills	<input type="checkbox"/>	ADHD	<input type="checkbox"/>
Other behaviours: please specify			

**Q25. In your experience, have you noted a child's ASD condition to restrict a parent's ability to plan and pursue the following?**

<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Educational interests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational and Employment interests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social and community interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreational and leisure interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q26. In your experience, have you noted a child's ASD condition to restrict a family's ability to plan and pursue the following?**

<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Recreational and leisure interests for family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social and community interests for family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Holidays / family excursions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q27. In your experience, have you noted a child's ASD condition to restrict the amount of quality time parents can spend with the following people?**

<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Their partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Their other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Their extended family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q28. In your experience, have you noted siblings of ASD children experiencing any of following?**

<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Feelings of being neglected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are worried and anxious about their siblings condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of resentment towards child with ASD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of guilt & fears they may be responsible somehow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of being treated unfairly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of isolation from peers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are More willing to Help with household chores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are very sensitive to Siblings needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are very sensitive to the needs of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Actively engage with sibling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q29. In your experience, do you feel the following provisions should be in place for families of ASD children in the future?**

<i>(Please ✓ as appropriate)</i>	Agree Completely	Agree	Neutral	Disagree	Disagree completely
Increase support and guidance during the diagnosis process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased opportunities for *ABA specific schooling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased Home and Respite Supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased provisions of Multidisciplinary therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The Appointment of a family Advocate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for general parent training in *ABA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for general Siblings training in *ABA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for general parent training in TEACCH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for general parent training in ASD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q29 Cont..... (Please ✓ as appropriate)	Agree Completely	Agree	Neutral	Disagree	Disagree completely
The need for a structured and comprehensive care plans to address a Child's future needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increase parental involvement in the creation and review of care plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased opportunities for ASD children to participate in community & social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased parental choice in the recruitment and appointment of Home support workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Greater sharing of information between professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional - advice highlighting services and entitlements available to families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional - advice on financial planning for a child's future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Training and teaching to be provided by a Qualified Behaviour Analyst- Trained to PHD level in Applied Behaviour Analysis / Board Certified Behaviour Analyst (BCBA)

**On behalf of the Charity: Parents' Education as Autism Therapists (P.E.A.T) the University of Ulster and Queens University Belfast. We would like to thank you for your time in completing this questionnaire and your willingness to participate in this research project.**

**Please save this document once you are complete and return via e-mail or post, on or before March 30<sup>th</sup> 2007.**

**E-mail:** [a.doherty@ulster.ac.uk](mailto:a.doherty@ulster.ac.uk)

**Post to:**

**Mr A. Doherty  
School of Psychology  
University of Ulster  
Coleraine Campus  
County L'Derry  
BT52 1SA**

**Thank you once again for your support.**

©



# MEETING THE NEEDS OF FAMILIES LIVING WITH CHILDREN ON THE AUTISM SPECTRUM

A RESEARCH PROJECT FUNDED BY THE ROYAL IRISH ACADEMY

The University of Ulster in conjunction with the charity Parents' Education as Autism Therapists (P.E.A.T.) and Queen's University, Belfast, are developing a strategic plan for '*meeting the needs of families living with children on the Autism Spectrum*'. It is anticipated this project will provide families and carers with the opportunity to inform and guide service provision on their specific needs and also provide P.E.A.T. with the information needed to further progress the following:

- ☐ A research-based strategy for meeting the needs of our members going forward over the next five years.
- ☐ Identify the necessary funding requirements to address the needs of families living with children on the Autism Spectrum.
- ☐ Promote collaborative working and partnerships with Academic, Statutory and Voluntary sectors.
- ☐ Identify measures which further enhance and strengthen the cross-border relationships that already exist.

During February 2007, we will be recruiting participants for this project. Participation is entirely voluntary, and you can withdraw at any point without giving a reason. If you decide to take part, we will ask you to complete a consent form, a questionnaire and maybe take part in a brief follow-up interview. All information collected about you will be strictly confidential. The results of the research will be used as a basis for the strategy document as well as journal publications and conference presentations.

Thank you for taking the time to read this.

## FOR FURTHER INFORMATION:

Please contact the Principle Investigator Dr Mickey Keenan at +44 (0) 2870324282 or e-mail [M.Keenan@ulster.ac.uk](mailto:M.Keenan@ulster.ac.uk).

## FOR EXPRESSION OF INTEREST:

Please contact the Research Associate: Mr. Alvin Doherty at +44 (0)28 70324979 or e-mail [A.Doherty@ulster.ac.uk](mailto:A.Doherty@ulster.ac.uk).

## OR VIA POST:

School of Psychology, University of Ulster Coleraine Campus,  
Cromore Road, Coleraine, County L'Derry, BT52 1SA



## Appendix 4

### Participant Information Sheet

#### **Meeting the needs of families living with children on the autistic spectrum**

You are being invited to take part in a study that is carried out by the University of Ulster in Conjunction with the Charity Parents' Education as Autism Therapists (P.E.A.T.) and Queens University of Belfast. Before you decide its important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask the researcher if anything is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

The number of children diagnosed with Autism Spectrum Disorder (ASD) in Ireland is increasing and is estimated to be ca 1 in 100. Statutory service provision normally focuses on the needs of the child and in some cases may provide respite care as an attempt to relieve the demands on the family unit. We would like to develop a strategic plan with regard to service provision that addresses the family unit as a whole, including recommendations for collaborative service provision to families living with Autism.

You have been chose to take part in this study because we think you may be able to help us inform and guide service providers on the specific needs of families living with children on the autistic spectrum.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, asked to complete a consent form, questionnaire and maybe take part in a brief follow-up interview. If you decide to take part you are still free to withdraw at any time and without giving a reason. Any decision to take part or decline participation will not affect the service provisions or entitlements your child or family currently receive or require in the future.

All information collected about you will be strictly confidential and any information leaving the university will have all identifiable information deleted. The results of the research will be used as a basis for the strategy document as well as journal publications and conference presentations.

This research is funded by the Royal Irish Academy under Developing Charity Strategy Through Partnership – (DCSP) and has been reviewed by University of Ulster Ethics Committee.

#### **For further information:**

- A. Please contact the Principle Investigator Dr Mickey Keenan at 02870324282 or e-mail [M.Keenan@ulster.ac.uk](mailto:M.Keenan@ulster.ac.uk)
- B. Please contact the Research Associate: Mr. Alvin Doherty at 02870324979 or e-mail [A.Doherty@ulster.ac.uk](mailto:A.Doherty@ulster.ac.uk)

Thank you very much for taking part in this Study

Dr Mickey Keenan     January 2007

## **Consent Form**

Research Title:

### **Meeting the needs of families living with children on the autistic Spectrum**

Name of Principle Investigator: Dr Mickey Keenan

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions
2. I understand that my participation is voluntary and that I m free to withdraw at any time
3. I agree to take part in the above study

Name of Participant	Date	Signature

Alvin Doherty	15 March 2007	
Name of researcher taking consent	Date	Signature

Dr Mickey Keenan		
Principle Investigator	Date	Signature

1 copy for participant and 1 copy for researcher

## Appendix 5

Ministry of Children and  
Youth Services  
Policy Development and  
Program Design Division

Specialized Services and  
Supports Branch

800 Bay Street  
6<sup>th</sup> Floor  
Toronto ON M5S 3A9  
Phone: (416) 327-4865  
Fax: (416) 325-5349

Ministère des Services à  
l'enfance et à la jeunesse  
Division de l'élaboration  
des politiques et de la  
conception des  
programmes

Direction de soutiens et  
services spécialisés

800, rue Bay  
6<sup>e</sup> étage  
Toronto ON M5S 3A9  
Tél : (416) 327-4865  
Télec : (416) 325-5349



October 18, 2007

Dr. Mickey Keenan  
University of Ulster  
Coleraine, L'Derry  
N. Ireland  
BT52 1SA

Dear Dr. Keenan:

Thank you for your e-mail to Premier Dalton McGuinty regarding the use of Applied Behaviour Analysis (ABA) methods for children with autism. I appreciate your taking the time to write about this important issue, and commend you for your work in your community to raise awareness regarding the role of ABA in meeting the needs of children with autism spectrum disorders (ASD).

The government of Ontario's vision is for children and youth to have the best opportunity to succeed, and the Ministry of Children and Youth Services (MCYS) has implemented a number of initiatives to assist children and youth with autism to achieve success.

The ministry is committed to providing evidence based services and supports to children with youth with autism and their families and it is widely accepted, based on the available research evidence, that use of Applied Behavioural Analysis (ABA) methods are effective in helping children with autism to learn.

The Ministry's overall budget for autism services for 2007/08 is approximately \$140 million. Funded programs include those that employ ABA methods such as:

- The Autism Intervention Program which delivers intensive behavioural (IBI) intervention services to children and youth diagnosed with autistic disorder or a disorder at the more severe end of the spectrum. IBI is based on the principles of ABA and refers to an intensive application of ABA for children with autism.

- The program was designed and developed in response to evidence that Intensive Behavioural Intervention is an effective treatment approach for children with autism.
- The ministry's support for the program derived from the fact that IBI services were being demonstrated to be effective, and parents of children with autism were in support of these services for their children.
- Prior to program development in 1999, the ministry commissioned a review of the literature regarding IBI treatment for children with autism. This review, which supported IBI services for children with autism, was undertaken by Dr. Adrienne Perry, currently at the Department of Psychology at York University in Toronto.
- In 2005, Dr. Perry undertook a provincial retrospective review of the Autism Intervention Program. Her findings included the following:
  - 75% of children improved in some measurable way during their involvement with the program;
  - As a group, children showed improvements in the severity of their autism, their cognitive level, and their adaptive behaviour (communication, daily living, socialization and motor skills).
  - Children who were relatively higher in functioning and younger (less than 48 months) at intake had more favourable outcomes.
  - Children who were involved with the program for longer durations (2 years or more) did better than those with shorter durations.
  - Parent stress and coping did not appear to be related to child outcomes.
- More detail on this review is available at [www.ontario.ca/oucomeIBI](http://www.ontario.ca/oucomeIBI).

The ministry also supports a number of capacity building initiatives that are based on the principles of ABA. These include:

- The School Support Program – Autism Spectrum Disorder which funds ASD Consultants to work with school boards to help teachers, principals and other educators to understand the unique learning needs of children with ASD.
- The College Graduate Certificate Program in Autism and Behavioural Science which prepares graduates to work with children and youth with autism employing methods of ABA.
- Training is provided to resource staff who work with child care centres to help them understand the unique needs faced by children with autism and to identify strategies for working more effectively with these children.

It may also interest you to know that in 2006, the Ministers of Children and Youth Services and Education jointly established the ASD reference group to provide advice on how to better support children with ASD in schools. The group's final recommendations are contained in the January 2007 report *Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools: From Evidence to Action*. The full report can be accessed at [www.edu.gov.on.ca/eng/document/nr/07.02/autismFeb07](http://www.edu.gov.on.ca/eng/document/nr/07.02/autismFeb07).


Informed by the work of the reference group, the Ontario Ministry of Education (EDU) also released a policy and program memorandum in May 2007 which directs school boards in the province to incorporate ABA methods into educational programs for children with ASD. MCYS worked with the Ministry of Education in developing this policy and was involved with training for school board staff regarding the policy directive.

In building a continuum of services and supports for children and youth with autism, the approach taken by MCYS has been to design programs and services that are based on the best available evidence. ABA figures prominently because the research literature supports the approach as effective in helping children and youth with autism learn. As well, the ministry has consulted with clinical and research experts, parents and academics in developing services and supports.

While we have made progress, there is more to be done. We are actively looking into ways to improve and build on the services we provide for children and youth with autism and their families.

Once again thank you for writing.

Sincerely,



Louise Paul  
Director  
Specialized Services and Supports

c: Premier Dalton McGuinty

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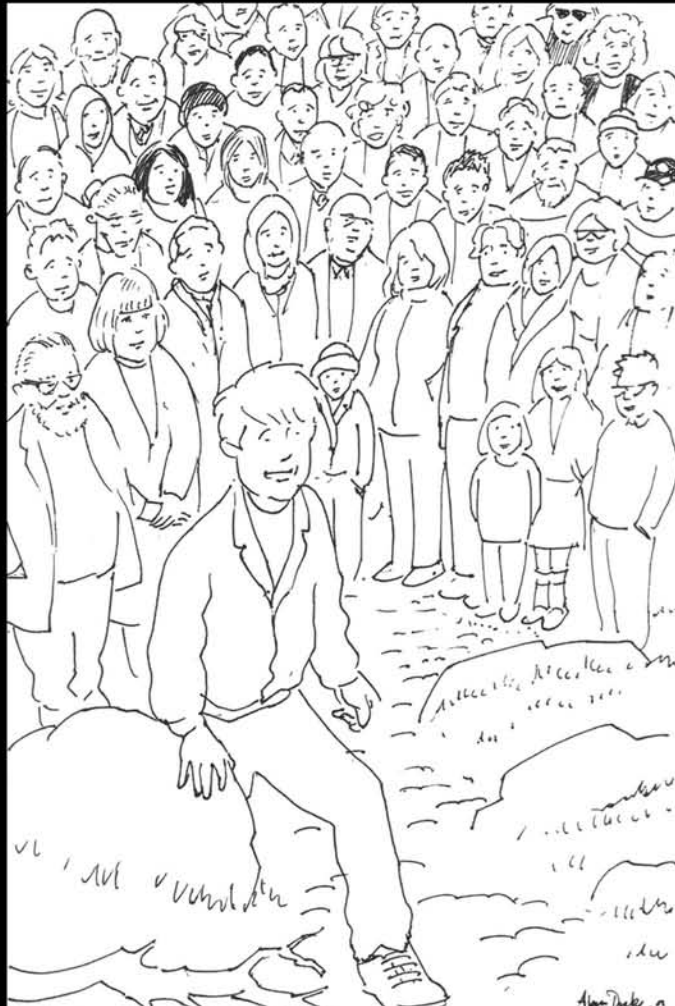
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